



CAU SOCIAL MOVEMENT SYMPOSIUM

October 2013

*How to Support a Social Movement to Advocate for the Ability
of People with Developmental and Intellectual Disabilities to
Achieve Economic Well-Being, Secure Access to Needed Service
and to Control Their Own Destinies*

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CAU Social Movement Symposium

Summary of Discussion

VAL BRADLEY AND CATHY FICKER TERRILL

2013

CAU Social Movement Symposium

Summary of Discussion

Background

On October 21st and 22nd of 2013, Community Access Unlimited sponsored a Social Movement Symposium at the Pleasantdale Chateau in West Orange, New Jersey. The purpose of the meeting was to bring together a group of people from the intellectual and developmental disability community, along with CAU Board Members and staff, to discuss trends in the field and the ways in which CAU could contribute to the expansion of a progressive inclusion movement that results in the improvement in the quality of life of people with intellectual and developmental disabilities. The following is a summary of two days of very rich and productive conversation.

Participant Direction

While everyone says they do participant self-direction, very few states and providers actually support broad access to a comprehensive and expansive model of self-direction. More troubling is that emerging funding constructs such as 1115 waivers, the “duals” demonstrations, and managed care in general do not have standards that outline specific expectations for the inclusion of self-direction. To expand access to self-direction, it will be necessary to embed expectations in regulations (e.g., regulations governing medical homes). Further, our field must support training and wide dissemination of information about the implementation of self-direction. Finally, we must find ways to use technology to expand the independence and person efficacy of people with intellectual and developmental disabilities.

Self-Advocacy

We must find ways to sustain self-advocacy. We need to emphasize the requirement (CMS) that individuals must be full participants in their individual service plans. These policies need to be strengthened to ensure that self-advocates are involved in all decisions regarding their lives and also with respect to public policy.

Self-advocacy funding needs to be built into the Developmental Disabilities Act, and the policy should emphasize and promote best practices. Funding needs to support the development of technical expertise among self-advocates with respect to federal policy like Medicaid, grant writing, and local organizing. The movement needs to be independent and sustainable; too often it is controlled by people who are not self-advocates. Most groups live from grant to grant and don't have an executive director who is a self-advocate. The problem is that it is treated like a program, not a movement. We need to go to the self-advocate leaders and ask how we can be helpful. We may need to fund small efforts in some states and build to state funding.

CAU Helping Hands has learned a lot about how to manage a successful self-advocacy organization. They know what self-advocates seek help with and what they need to learn, they discuss legislation, they go to conferences, they support major reforms like deinstitutionalization, they pay attention to how the process of moving people to the community is implemented, and they talk to parents.

Technology

There is untapped power in the use of technology in the health and wellness of people with intellectual and developmental disabilities. Technology can be used for care prompting, coaching, education and patient promotion. Social media should also be a tool for health promotion including the use of short videos on healthy lifestyles as well as health self-assessments. Access to technology should be a right for people with disabilities.

Ensuring Valued Outcomes in Managed Long Term and Health Care

Currently, most managed care contracts do not include expectations regarding valued outcomes such as employment, self direction, relationships, and community inclusion. Unless such metrics are built into such contracts, there is very little hope that they will be measured, let alone shared with the public. Outcomes have to be tangible and measurable. People and families using managed long term and health care should have the tools necessary to evaluate their care and the value of their supports.

Further, contracts should include standard of care guidelines for issues like prescription of psychotropic medications (e.g., Canadian health guidelines).

Other issues to address in managed care include the ways in which we can ensure person centered practices and planning are followed, and the role that the participant's representative plays.

We should keep in mind that managed care is not a program, it is simply a mechanism for funding services using capitation. We should also face up to the fact that managed LTSS care will spread rapidly across the country in the next few years. Whereas Arizona, Michigan, and Wisconsin took a decade to roll out managed care financing for LTSS, the timeframes in a lot of states are now much shorter. We need to be prepared to influence the structure of these initiatives.

We need to make sure that the future direction of managed healthcare has a primary focus on prevention. We need to look at federally qualified health centers as a model of what good healthcare should be.

Employment

Expanding the availability of competitive employment among people with ID/DD is the antidote to income inequality. If you have more money you are less poor. Employment is a critical goal for any progressive policy. Why do we spend public resources on “day wasting” that creates no income? We need to put employment first. We need to start building work skills from the time people are young—we can't wait until people are 22 to 25 years old to start introducing those skills. Skills include building financial literacy and benefits counseling and leadership. We need to incentivize employment in order to make it worthwhile for people to provide support and to make employment a desired outcome.

Absence of Voice from Racial, Ethnic, and Linguistically Diverse Groups

As demographics are rapidly shifting, individuals from racial and ethnic groups other than non-Hispanic white will collectively outnumber the white population by 2042; yet, voices from this segment of the DD community are notably absent in most major DD research and policy groups as well as in major initiatives such as self-determination transition to post-secondary education and employment for people with DD. Every major initiative needs to disaggregate their outcome data by racial/ethnic groups so we can document whether all sub-groups are benefiting from these national initiatives, and if not, what needs to happen to assure greater equity. Investments need to be made to promote greater racial and ethnic diversity in the leadership of parent and family support programs, the self-advocacy movement, leadership of DD and related service systems, and in DD research units.

Medicaid

There are possibilities for expansion and enhancement of services and supports for people with ID/DD in the recent Medicaid funding authorities including 1915i and 1915k. There is a need to disseminate information on new possibilities to a wider range of stakeholders. Another major progressive change would be to allow portability of

Medicaid across states—in other words, Medicaid offerings, eligibility, and level of reimbursement should be the same across the country.

Political Strategy

The aim of the group should be to design a public policy campaign that captures the hearts and minds of people feeling left out and that outlines specific ways to realize progressive change. We have successful laws and Supreme Court rulings but little progress in attitude changes. The next step is to begin with people in the room and then expand to people with different worldviews. To bolster the case for reform, we should take advantage of research that is already out there and repackage it; people and decision-makers are moved by data. Use data—especially on social inequality—to define common concepts and common interests.

The American dream is that the circumstances of one's birth should not dictate one's future. Unfortunately, that dream is increasingly unattainable. There are probably a lot of people who are concerned about the loss of this dream but are afraid to admit it. We need to help them come out of the closet and embrace political change. We can take some lessons from Richard Wilkinson's work and could start by targeting a few states (e.g., NJ) to convene people to discuss and implement. As part of the process we should hold a mirror up to ourselves to see what we are perpetuating. We should ask people what kind of world they want to live in. We also need to couch our ideas in language that people understand and we need to be sensitive to the ways in which various age groups process and respond to information. Participants need to be committed to bringing others to the table.

To attract others who share similar values and circumstances, we need to concentrate on the need for generic supports such as housing (e.g., distribution of rental subsidies), attendant services, healthcare, transportation and employment.

To carry out the strategy, we will need to develop a logic model that displays the inputs, processes, variables and outcomes; in other words, a well worked out strategic approach. We also need to take advantage of social media through the use of videos and other means. We also need to explore ways of placing stories in the news. The campaign needs to attract our familiar allies but should also reach out to groups similarly situated, like elders and veterans. This will require decisions about our focus—is it on people with disabilities and their families or a broader group?

We should also focus on changing attitudes especially in the educational and healthcare systems. We need to influence the training that health care and education professionals receive.

Parents need to be part of the movement. In the past they have been a force for good; however, they can also stand in the way of change—as evidenced by opposition to deinstitutionalization, fear of loss of benefits if people get employed, and support for gated communities. We need to cultivate parent advocates that agree with our values.

Quality Indicators in Managed LTSS for People with Disabilities

CAU Symposium | October 2013

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Quality Indicators in Managed LTSS for People with Disabilities

CAU Symposium | October 2013

1. Overview

Managed care generally conjures up negative images among most people with disabilities and advocates. This is easy to understand given the terrible outcomes some have experienced under managed care programs for acute and primary medical care. As states rapidly move toward managed care for long-term services and supports (LTSS), alarm is warranted given the poor track record of states in actually managing and monitoring the work of those entities charged with “managing” the delivery of medical care, treatment, and services and supports for people with disabilities.

Yet, as one considers the pitfalls of managed care, one must also consider the pitfalls of fee for service. Managed care, like fee for service, is simply a vehicle for payment. It is only as good, or as bad, as the parameters defining its operation. Most states are inherently bad in assuring and improving quality regardless of the funding structure.

That said, managed care is being used in nearly every state Medicaid program for some, if not all, medical care. (Alaska and Wisconsin are the only two states with no involvement.) What is different now is the states’ effort to include LTSS, and this effort is moving forward rapidly. In fact, CMS data estimate 27 states will be using managed care to fund LTSS within the next two years. While not all of them are including people with IDD, many are. Further, it is unlikely that existing carve-outs for the IDD population will continue indefinitely.

I am of the mind that those of us working as advocates and policy-makers should be at the table in each state as managed care is discussed and framed. Even if IDD is excluded initially, what is shaped will undoubtedly become the basis for future LTSS. Our absence in this process will result in ill-defined outcomes for people with disabilities in the long run. We should be present, inserting our non-negotiables at every opportunity.

Among the early adopting states we see dramatically differing programs. These include Arizona, which implemented a fully managed care system in the late 1980s in their ALTCS 1115 waiver. In this instance, Arizona’s DD administration acted as the managed care entity for people with IDD. Michigan has been engaged with managed care since 1998 through a combination 1915 b/c waiver, creating a network of pre-paid capitated managed care organizations (MCOs) with strong values and person-centered planning in regulations. For people with IDD, behavioral health needs, or aging, funding is managed through a network of quasi-governmental community boards or nonprofit organizations with profits going into serving people on their waitlists. Wisconsin began implementing managed care in 1999, again

through a 1915 b/c Family Care waiver. Self-direction remains an option through their 1915 c waiver as a standalone for anyone who wants to self-direct services.

States newly looking at including people with IDD in managed long-term services and supports (MLTSS) include California, Idaho, Illinois, Kansas, Massachusetts, New Hampshire, New York, Ohio, Virginia, and Washington state. These states are in various stages of implementation and proposal; however, their approaches are radically different. Of note, New York is proposing a framework initially to serve only its IDD population. New York is taking its time in a fully transparent process that includes people with disabilities, families, providers, and other stakeholders in designing the structure. On the other end of the spectrum, some states are rushing forward without transparency and with little to no involvement from the disability stakeholder community.

2. Why would states look at managed care?

Managed care allows state officials to achieve budget stability over time through capitation. It limits states' financial risk, passing part or all of it on to contractors by paying a single, fixed fee per enrollee, and it allows one entity to be held accountable for controlling service use *and* providing quality care. MLTSS refers to an arrangement between state Medicaid programs and contractors through which the contractors receive capitated payments for LTSS and are accountable for quality, cost, and other standards set in the contracts. Capitation can be for all services or selected services. Contractors can be local, regional, or national. LTSS populations include persons with age-related, physical, or intellectual/developmental disabilities. Many of these individuals may also have serious mental illness.

CMS will hold states accountable for quality using some very basic measures, including: timeliness of completing level of care assessments; timeliness of initiating home and community-based services (HCBS); people receiving the services authorized; the number of successful transitions to the community from institutions or nursing facilities; the level of person-centeredness of service planning; whether or not people are engaged in volunteer or paid work; the ability of people with disabilities to self direct services and their satisfaction with services.

3. States must identify non-clinical outcomes in contracts

The medical side of managed care uses long-standing measures to assess quality and personal satisfaction. Using measures from the Healthcare Effectiveness Data and Information Set (HEDIS) and the Consumer Assessment of Healthcare Providers and Systems (CAHPS), states hold managed care companies accountable to achieve certain clinical outcomes. Yet there is no standard set of agreed-upon measures that look at nonclinical outcomes important to people with disabilities in LTSS settings. These are somewhat nebulous in that the IDD field lacks a robust data collection effort around commonly agreed-upon measures. CQL's Personal Outcome Measures and the National Core Indicators provide the field with both individualized and aggregate measures, but the challenge is integrating them with state contracts with

managed care companies. One way of achieving this is by providing financial incentives if MCOs/providers achieve certain outcomes.

4. Possible outcomes to consider

Some outcomes to consider include holding MCOs accountable for increases in the percentage of people with disabilities placed in integrated employment or the number of hours that people with disabilities are engaged in meaningful volunteer work. Medicaid Buy-In data show strong correlations between employment and lowered health care claims against Medicaid. Another could be increased levels of independence and social skills. Another could be satisfaction and quality of life indicators: stable housing of the person's choosing; transportation available when desired; an affirmation on not being lonely; and of course, freedom from abuse and neglect.

4.1 ANCOR's Funding Reform Checklist

Typically, disability groups oppose the use of managed care in the delivery of LTSS. Principles held dear by the disability community, such as person-centered planning and individual budget authority, challenge thinking as to how they will play out in a managed care framework. Yet, increasingly states are moving forward with a variety of capitation funding strategies.

LTSS must ensure full citizenship and engaged community participation for people of all ages with disabilities. A majority of states are presently seeking integrated finance strategies (including capitation) in response to extensive Medicaid reform efforts nationally and by the states. People with disabilities, long carved out of such efforts, are now being included in state proposals. These cost containment efforts are being directed to supports and services for people with disabilities, people who are aging, and individuals who are dually eligible for both Medicare and Medicaid. States are increasingly attempting to integrate services for physical health, behavioral health, and developmental disability LTSS. LTSS are being fully included and integrated into states' proposed 1115 research and demonstration waivers or combined 1915 (b) freedom of choice and 1915 (c) home and community-based services waivers. Individuals with disabilities should receive LTSS that improve quality of life and produce valued outcomes.

It is critical for disability stakeholders to be at the table when discussions take place in states rather than just advocating to be carved out. States are seeking ways in which to curtail spiraling costs and shift the onus for quality onto managed care companies. We must be present to define the parameters of quality, the expected outcomes, and standards of measurement—especially for non-clinical outcomes associated with LTSS. As many organizations, ANCOR developed a *Funding Reform Checklist* to assist its members in advocating with policymakers to assure reasonably good outcomes for states moving LTSS to a managed care framework. As states propose fundamental shifts and dramatic changes to the way LTSS are funded, this checklist can be a useful tool in guiding the dialogue between states and stakeholders.

Content areas include the following:

- Stakeholder Engagement
- Mission and Vision, Core Values/Guiding Principles
- Assessment and Rate-Setting Methodology
- Performance Measures and Metrics
- State Responsibility and State Regulations
- Financial Risk Between the State and the MCOs
- Requirements for the MCOs
- Health Information Technology (HIT) and Electronic Health Records (EHR)

By adhering to the principles outlined in the checklist, opportunities for system change and innovation exist. Imagine a managed care system that reimbursed based on the number of people in competitive employment or being supported in their own home? Imagine incentives being paid for people identifying as not being lonely? Before dismissing this as crazy, we must acknowledge that the current fee-for-service system fails repeatedly when it comes to providing meaningful outcomes to people with disabilities.

5. Future uncertainties

A few years ago we heard talk about *the new normal*, and it now begs the question, “Are we there yet?” With so many uncertainties looming one would have to argue, “Probably not.” Since the recession began we had both federal and multiple state elections, the recent Supreme Court ruling on the Affordable Care Act, pending federal cuts to Medicaid and a still unmanageable federal deficit. States are scrambling to control Medicaid costs through managed care, accountable care organizations, primary care case management and coordinated care programs. Federal agencies are rapidly proposing changes to rules for companion care, employment supports, and the definition of community for home and community-based services programs.

As disability stakeholders we must stay focused and challenge assumptions. We must educate people with disabilities and their families to understand the changes ahead. We must do a better job of managing expectations as funding shifts and programs change. We are up to this challenge.

Managed Care and Self-Determination: Opportunities and Challenges

CAU Symposium | October 2013

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Managed Care and Self-Determination: Opportunities and Challenges

CAU Symposium | October 2013

1. Overview

This issue paper attempts to provide some structure, information, and discussion points on what at first glance are potentially antithetical concepts: managed care and self-determination. The issues we need to address are complex, and they differ whether one is talking about managed health care, managed long-term care, or self-determination. This paper provides snippets of information lifted from a range of sources to illustrate the complexity of the issues and the need for much better data to help guide our discussion. And it ends with a few starting questions.

In reality, one of the key challenges we face is a lack of information on successful ways to integrate managed health care and managed long-term care—which is increasingly the way future service models seem to be moving. We have some good starting principles on self-determination, but these need to be translated into specific strategies and tools that can work in whatever managed care structures of health care and long-term services and supports emerge from the current environment of uncertainty. For example, in the issue brief “People with Disabilities and Medicaid Managed Care: Key Issues to Consider,” the Kaiser Family Foundation raised two central points—and these same two points represent critical challenges faced by policymakers who seek to transition the service system to managed care:

- Establishing capitation rates for persons with disabilities poses special challenges
- Risk-based managed care for persons with disabilities is not likely to generate short-term savings

The report goes on to say “No national database exists to support analysis of important managed care measures.” So the current move by many states to transfer people with disabilities into managed care plans is surrounded by more questions than answers at the present time. One central set of questions that does not seem to feature significantly anywhere in these proposals relates to persistent health disparities/health inequalities between people with cognitive disabilities, including intellectual disabilities, and the general population: How might these inequities be better addressed under managed care? *The planned transition of people with intellectual disabilities into managed long-term supports and services presents similar challenges and questions.*

What people are probably willing to agree on “in principle” is the goal stated in the National Council on Disability report on *Successfully Enrolling People With Disabilities in Managed Care Plans: Guiding Principles*: that “the central organizing goal of system reform must be to assist

individuals with disabilities to live full, healthy, participatory lives in the community.” A key strategy for achieving this goal might be to encourage the adoption of the principles of self-determination as the guiding tools in system redesign and reform. But while this idea presents a major opportunity it is also, as yet, an untested principle.

My perspective on these issues is shaped by my experiences during a 30+ year career in the University Center for Excellence in Developmental Disability (UCEDD) network. Currently the Westchester Institute for Human Development (WIHD) UCEDD is involved in these issues in many ways. WIHD is a large provider of health care (primary care and specialty care), psychiatry services, and dental services for people with disabilities. We serve over 5,000 people with IDD, and we collaborate with more than 100 providers of long-term supports and services and with families. WIHD not only trains health care professionals in clinical skills, we also train them in understanding the hopes, dreams, and lifestyles of the people we serve and in promoting self-determination. WIHD demonstrates and evaluates innovative approaches to support increased participation of people with IDD in their health care experience and in taking charge of their health. In the area of long-term supports and services, WIHD provides individualized supports to assist people in getting the lives they want as full members of their community. We provide Medicaid Service Coordination, benefits navigation, support for individualized housing, support for competitive employment, and more. Finally, WIHD is involved in various local, state, and federal activities that help people with IDD live healthy, productive lives as full members of their community.

What follows is a discussion of some of the challenges and opportunities related to what might soon be the forced marriage of managed health care and long-term care for people with IDD. There are some critical health care challenges, but there is also the opportunity to use the goal of maximizing self-determination as a vehicle for innovation in future combined service models. The discussion starts by defining some key terms and presenting some data on the extent of unmet health needs among people with IDD. Another data set highlights the potential of looking at health care and long-term care as interrelated expenditures for achieving overall population health goals. There is also some discussion of the ways that health information technology is enabling key health improvement measures of the Affordable Care Act to be achieved. Using health information technology in systems redesign and for the creation of better models of individualized care offers yet another opportunity for innovative change that could enable self-determination to become a key reorganizing strategy.

1.1 Two starting points: some definitions and principles

Definitions:

- **Managed Health Care:** Achieve better health care and health outcomes while controlling or reducing health care costs.
- **Managed Long-Term Supports and Services:** Coordinated services and supports to assist individuals with IDD to live full lives in the community; encourage greater

equity in community living supports and services for people with IDD while controlling overall service costs.

- **Self-Determination:** People who are self-determined make things happen in their own lives. They know what they want and how to get it. They choose and set goals, then work to reach them. They advocate on their own behalf, and are involved in solving problems and making decisions about their lives.

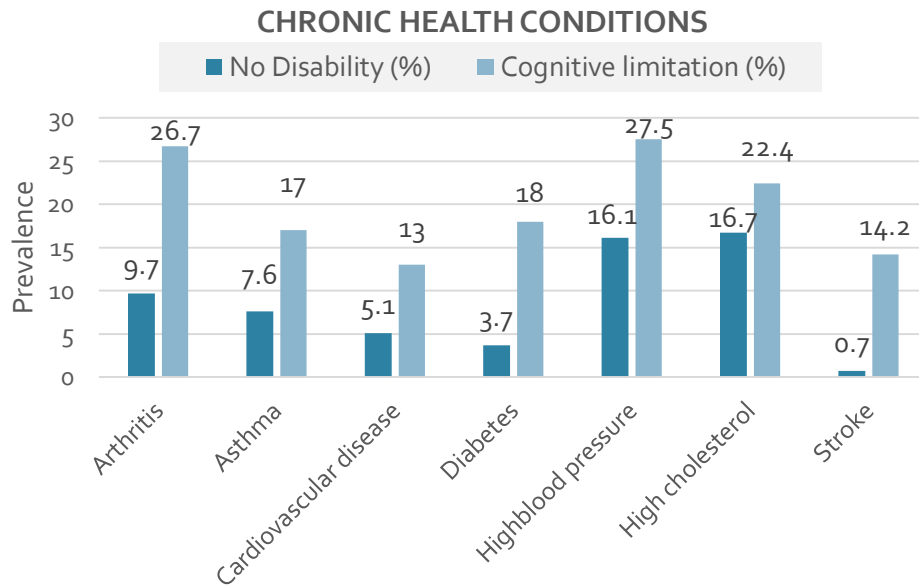
Some guiding principles for including self-determination in managed care

- National Council on Disability (in conjunction with the National Association of State Directors of Developmental Disability Services : Examples of guiding principles for the design and operation of Medicaid Managed Care programs for people with chronic disabilities—
 - The central organizing goal of system reform must be to help people with disabilities live full, healthy, participatory lives in the community.
 - Managed care systems must be designed to support and implement person-centered practices, consumer choice, and self-direction.
 - Working-age enrollees with disabilities must receive the supports necessary to secure and retain competitive employment.
 - Families should receive the assistance they need to effectively support and advocate on behalf of people with disabilities.
 - States must ensure that key disability stakeholders are fully engaged in designing, implementing, and monitoring the outcomes and effectiveness of Medicaid managed care services.
 - Managed care delivery systems must be capable of addressing the diverse needs of all plan enrollees on an individualized basis.

1.2 A key issue for managed health care: persistent health disparities among people with IDD

- Life expectancy at birth: U.K. report on premature deaths of people with learning disabilities
 - Men with LD died on average 13 years sooner than the general population
 - Women with LD died on average 20 years sooner
 - 22% of people with LD were under 50 at time of death compared with just 9% of the general population
 - No equivalent data for people with IDD in the United States, but the Australian data is very similar to the U.K. data

- Chronic disease prevalence: Age adjusted prevalence rates for chronic health conditions, MEPS 2006:



(Reichard, Stolze and Fox, 2011)

- Adults with cognitive disabilities and diabetes are significantly more likely to have four or more chronic illnesses

1.3 The possible benefit of looking at the interrelationship of health care and social care (long-term supports and services) expenditures for achieving optimum health for people with IDD

- The social determinants of health agenda is captured annually by the Organization for Economic Cooperation and Development (OECD) for its 34 member countries. The United States does not fare well. The 2009 Health Statistics & Indicators and Social Expenditures Databases showed that while the United States ranked #1 in per capita health expenditures, it ranked #27 or lower on all the indicators of population health such as life expectancy at birth.
- Why is this? In OECD for every \$1 spent on health care about \$2 is spent on social care including long-term services and supports; in the United States for every \$1 spent on health care, about 55 cents is spent on social care. Moreover, the United States ranks #34 among the countries of the OECD in the rate of obesity in the general population. As we know, rates of obesity can be much higher in people with IDD.
- So the integration of managed health care and managed long-term care has the potential to achieve a better balance of health care versus long-term care expenditures so can we develop good models to build on.

2. Some concrete steps to address barriers and/or reinvent policy or practice

2.1 Adopt best practices in health care for people with IDD

- Use health status checklists and practice standards specifically developed for the care of people with IDD: the Pomona health indicators checklists used in the European Union; the comprehensive health assessment tool used in Australia; and the Primary Care of Adults with Developmental Disabilities: Canadian Consensus Guidelines—for providers and caregivers
- Support specialized primary care provider training in IDD medicine
 - Queens University, Canada: Family Practice Residency Program
 - The Netherlands: Specialist ID Physician Qualification
 - United States: American Academy of Developmental Medicine and Dentistry, National Curriculum Initiative for Family Practitioners
- Adopt Patient-Centered Medical Home standards of care for people with IDD
- Adopt “meaningful use” of electronic health records to document that standards of care are being met and that key health outcome indicators are being achieved
- Promote health self-advocacy through the use of smart technologies and applications such as the WIHD/AbleLink Technologies “My Health, My Choice, My Responsibility” app and direct response health care experience surveys

2.2 Develop specific tools and strategies to determine whether self-determination is being achieved in health care and long-term care for people with IDD

- Develop user-friendly personal outcome measures
- Use accessible survey technologies to develop new tools that will enable ongoing feedback from consumers on their experience of the care they are receiving
- Develop strategies for caregiver training and support in maximizing self-determination

3. Opportunities for systems change and innovation

- Innovative use of **health information technology** is already creating system change in the delivery of health care, leading to better outcomes. There are huge opportunities in this area to improve the health of people with IDD.
- **Innovative smart technology** has the potential to play a role in promoting self-determination in both health and community living. The question is this: How can those technologies be made available at sufficient scale and cost to enable independent living for the rapidly growing numbers of people who will require long-term services and supports but who also want to live as independently as possible?
- We can make good on the promise of strong **primary care** for people with IDD in managed care.

- We can work to achieve better **coordination/ integration** of health care and long-term services and supports.
- New ways of doing business provide an opportunity for innovative approaches that are based on **choice and control**.

4. **How will this further enhance the empowerment of individuals with IDD?**

The ability and the opportunity to exercise choice and control is the essence of empowerment. This paper has attempted to reconcile two antithetical concepts—managed care and self-determination—by exploring issues in future systems design built on these key principles of self-determination. It has focused on issues and strategies that will promote self-determination in both managed health care and managed long-term services and supports. But it will take concerted advocacy from all of us to turn the potential of self-determination into a reality that leads to enhanced empowerment for people with IDD.

Inequities in Access to Services for Individuals at the Intersection of Race and Disability and Their Families

CAU Symposium | October 2013

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Inequities in Access to Services for Individuals at the Intersection of Race and Disability and Their Families

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1. Description of the topic area

This topic area focuses on creating a sustainable infrastructure that will, over time, prepare the developmental disabilities (DD) field to meet the needs of the growing number of individuals with disabilities from diverse racial, ethnic, and linguistic backgrounds. It is well known that by 2042 there will be no majority racial/ethnic group in the United States, and by 2050 the nation's population will be 46% non-Hispanic white and 53% persons of color (30% Hispanic, 12% Black, 1% American Indian, 8% Asian-Pacific Islanders, and 3% multiracial), a demographic already present in some states. Disparities in access to services for individuals from racial and ethnic groups other than non-Hispanic white have been documented in every public service system, and evidence suggests that the growing economic inequality in our country continues to feed the vicious cycle of limited access to quality employment, education, healthcare, transportation, housing, and other services for those struggling for a better life.¹ When individuals also have a disability, the barriers to necessary services are indisputably exacerbated, but our field lacks solid research on how these two attributes interact. This paper is about chronic inequities experienced by individuals at the intersection of race/ethnicity and disability.

Because racial, ethnic, and linguistic disparities have been studied most extensively in the healthcare arena, this paper borrows heavily from this body of research and applies it to people with disabilities. Until we have research to demonstrate otherwise, this paper argues that race, ethnicity, and language spoken contribute significantly to chronic inequities experienced by individuals at the intersection of race and disability, and the effects of race, ethnicity, and language spoken may be more pernicious than the presence of a disability. Three points will be made. First, it is argued that individuals at the intersection of race and disability experience significant barriers to equity and justice within the disability system. Second, opportunities for system change and innovation must systematically address the role of racism and discrimination at all levels (individual, group, and system) in explaining and solving chronic inequities for individuals at the intersection of race and disability. Third, steps to address chronic inequities for individuals with DD from racial and ethnic groups other than non-Hispanic white will require reinventing and disrupting current policy and practice.

¹ Balcazar, F.E., Suarez-Balcazar, Y., Taylor-Ritzer, T, Keys, C.B. (eds). *Race, culture, and disability: Rehabilitation science and practice*. Sudbury, MA: Jones and Bartlett Publishers, 2010.

2. Overview of the issues

Three terms are frequently used to describe this topic area: disparity, inequality, and inequity. While all are inter-related, the key issue for this paper is addressing “inequities,” which refer to situations where inequalities or differences exist between groups, but the inequalities are viewed as unfair and unjust². In 2000, Camara Jones³ boldly noted that race-associated differences in health outcomes have been consistently documented in this country for decades. When applied to the focus of this paper, she would argue that, in a race-conscious society such as the United States, this may be due to the conscious and unconscious social classification of individuals with DD who are members of racial, ethnic, and linguistically diverse groups into categories of inferiority, potential threat, and/or other negative attributes, leading to differential responses and opportunities afforded based on the individual’s skin color, appearance, or accent by public servants and service personnel—from sales clerks to police officers, property owners, judges, employers, and educators. Jones argues that the variable “race” has moved silently from a non-biased clinically-relevant biological construct thought to explain differences in health and disease²⁻⁴ to a pernicious social construct called racism, prejudice, and discrimination that profoundly impact the daily life experiences of people at the intersection of race and disability. Although evidence of this in the disability field is late in coming and still scant, data and publications on inequities for racial, ethnic, and linguistically diverse individuals with DD are growing. As an example, in an examination of factors associated with service use and expenditures for over 175,000 individuals with DD who received developmental services from California’s system of 21 regional centers during 2004-2005, social science researchers at the University of California San Francisco found indisputable evidence that when client needs were controlled, clients from all racial and ethnic minority groups were found to be *less likely to receive any services at all* (unserved); and for those who received services, members of all racial and ethnic minority groups *had significantly lower expenditures*. Specifically, African Americans received \$1,320 less, Asian/Pacific Islanders \$2,560 less, and Hispanics received \$3,510 less than white clients matched on age, need, and Medicaid status.⁴ There is a long history of differential treatment of students in public schools, with patterns of Black students over-identified for special education classes (for students with intellectual disabilities, aka mental retardation, and/or severe emotional disturbance) and white students over-identified in classes for learning disabilities and for the gifted and talented. In an era of impressive progress in the employment of people with disabilities at all levels, a white paper of the National Black Disability Coalition New Jersey chapter⁵ noted that employment rates for people of color were significantly lower than for white people with disabilities.

² Whitehead, M. (1991). The concepts and principles of equity and health. Cited in O.C. Pokras & C. Baquet. (2002). What is “Health Disparity”? *Public Health Reports*, 117, 426-434.

³ Jones, C.P. (2000). Levels of racism: A theoretical framework and a gardener’s tale. *American Journal of Public Health*, 90(8), 1212-1215.

⁴ Harrington, C., & Kang, T. (2008). Disparities in service utilization and expenditures for individuals with developmental disabilities. *Disability and Health Journal* 1: 184-195.

⁵ Gravel, J. (2009). *People of Color Office on Disability White Paper*. National Black Disability Coalition, New Jersey Chapter. Unpublished manuscript: July 30, 2009. www.blackdisability.org.

When individuals with disabilities from racial, ethnic, and linguistically diverse groups receive a different array of educational, behavioral, social support, employment, and other services and fewer public dollars for needed services than white peers with a comparable disability and of comparable severity, there is an egregious threat to the independence, productivity, and self-sufficiency goals articulated by the Rehabilitation Act of 1973, PL 93-112 and the civil rights of this population. Addressing the issue of inequity and justice for individuals at the intersection of race/ethnicity and disability is no longer discretionary, but essential for the developmental disabilities field.

3. Opportunities for system change and innovation

The need to address racial disparities in accessing healthcare and related services is not a new topic. Several federal agencies—including the Office of Minority Health in the Department of Health and Human Services (DHHS), the Health Resources and Services Administration of DHHS, and the Centers for Disease Control and Prevention’s Office of Minority Health and Health Equity—have directly articulated a commitment to eliminate health disparities. However, this commitment has not been made by the disability community, with the exception of laudatory efforts by the National Institute for Disability and Rehabilitation Research. Other agencies have been relatively silent on this issue when compared to enthusiastic investments in self-determination, post-secondary education, self-advocacy networks, and employment in the DD field.

For the near future, this paper describes three pivotal opportunities for system change. *First*, the **disability community must learn to actively engage in a meaningful conversation about race, racism, and discrimination (conscious and unconscious)**. While very likely uncomfortable for many, until the disability community can openly discuss preconceived notions or stereotypes about individuals who have a different skin color, carry different values related to their culture, and/or speak a different language, those who hold the power of distributing resources to those who need them will continue to see these individuals as “outsiders” to the mainstream culture with whom they are more familiar and comfortable. Without talking about these differences, there is no opportunity for people on the inside and the outside to find common ground. It is only with intimate knowledge of those seen as different that stereotypes can be broken.

Second, of the three levels of racism she describes (institutional, personally-mediated, and internalized), Jones⁶ argues that **institutionalized racism** (which refers to “differential access to the goods, services, and opportunities of society by race,” which is normative, sometimes legalized, and codified in our institutions through custom, practice, and law) **is the most important and fundamental to confront** before change can occur within the other two levels. Institutionalized racism manifests itself both in material conditions and in access to power. Institutional racism is especially dangerous because there is no identifiable perpetrator; in fact, its effects are often evident as inaction in the face of need or silence in the face of inequity.

⁶ Jones, C.P. (2000). Op. cit.

Third, we must **consciously and deliberately give voice to** those from **racial, cultural, and linguistically diverse groups** of people with DD and their families who are unserved, underserved, and underrepresented. The disability community has successfully embraced the value “**Nothing about me without me**” for individuals with disabilities and their parents/family members. It is now time to apply this principle to those who are not at the table—individuals at the intersection of race and disability, their family members, community-based organizations that fill gaps in mainstream service systems, and promoting the professional development and leadership of underrepresented minority students, staff, and university faculty.

4. **Concrete steps to address barriers and/or to reinvent policy or practice**

1. Deep investments to facilitate building the capacity of DD Network organizations to have a conversation about race, discrimination, and racism so that honest discourse to address barriers can occur. Such a discussion involves sharing power and can best be taught by those who have the lived experience or have lived in the communities which are currently un-served or underserved.
2. Deep investments in workforce diversity—that is, minority pipeline programs at all levels of career ascension and research to support the science underlying successful programs that can be replicated.
3. Deep investments to build the capacity of the DD network to authentically collaborate and partner with ethnic-focused community-based organizations. They are the trusted gateway to underserved minority communities who will build the bridge between underserved communities and the DD network that is attempting to serve them. The DD network should not try to be the gateway to minority communities; instead, it should participate in active meaningful commerce through a gateway that is owned by the communities the network is trying to reach and support.

5. **Anticipated Outcomes for People with IDD and the Community**

1. Access to services by un-served and underserved people with IDD who are members of racial, ethnic, and linguistically diverse groups other than non-Hispanic white will increase as will utilization of needed services, leading to the elimination of inequities over time.
2. The racial and ethnic diversity of the leadership of major stakeholder groups will reflect the racial and ethnic diversity of the people they serve, including but not limited to UCEDDs, DD Councils, Disability Rights organizations, leadership of DD service systems in states, policymakers, family-driven education, advocacy and support agencies, self-advocacy organizations, and leaders in key federal agencies. Leadership development of people currently absent from the table will require financial and program investments.

Technology and Self-Determination

CAU Symposium | October 2013

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Technology and Self-Determination

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1. Overview

Technology surrounds us and sometimes overwhelms us. But for the millennium generation it is a simple fact of life. Smart devices are never far from their hands, and these devices have become extensions of how they organize and live their lives. The ability of smart technologies—iPhones, iPads, Androids, and tablets—to extend and deepen relationships and lives is a social change on a par with the invention of the printing press.

But these advances in technology are only slowly making their way into the daily lives of people with intellectual and developmental disabilities. Their potential to enable and promote the goal of self-determination and enable individuals to lead fuller, more self-directed and inclusive lives is still only in the pilot-testing phase.

Smart technologies are promoting an exponential growth in software applications that can address a range of functional limitation. So for example, people who are blind or visually impaired easily master the special touch-screen swipe commands to access all the features of a smartphone. Most applications now come with voice command or voiceover descriptions of functions that can both control the capabilities of the device and give feedback as to whether it is doing what the person intended. These features can be of similar benefit to individuals with IDD.

Applications exist that can support independent use of transportation services, coach an employee on how to perform their job to the standard expected, and support independent living through access to meal planning and other daily living skills. Smart devices are also easy to use to create individualized care plans for individuals with special care needs because of health or physical disability issues. Additionally, the real-time nature of smart technologies makes them useful for monitoring activities as they occur (to track a daily walk for example) or for prompting and coaching individuals on when and how to engage in a wellness activities such as cleaning their teeth.

Above all, smart devices are powerful enablers of social interaction: instant messaging and other capabilities help support personal relationships in very spontaneous and powerful ways. Self-determination is meaningless if there is no community through which to live one's life and to feel valued and recognized for who one is. So the recent creation of an accessible Facebook page for people with intellectual disabilities, and voicemail instead of email, become tools for making and maintaining relationships that transcend barriers of distance and transportation. They enable virtual communities to exist alongside communities defined by geography and face-to-face relationships.

The other technology dimension behind the effective use of smart technologies for any purpose is the way they take advantage of cloud-based computing strategies. Applications, surveys, and customization can all be delivered directly to an individual's device simply through a WiFi or cell phone plan connection. Similarly, completed responses to surveys or the results of wellness activities can be sent to secure accounts in the cloud.

Self-determination is all about people making things happen in their own lives. Knowing what they want and how to get it. They choose and set goals, then work to reach them. They advocate on their own behalf, and are involved in solving problems and making decisions about their lives. Smart technology and the access to information that it brings should be central to achieving this goal for people with intellectual and developmental disabilities in the same ways they are for the rest of us.

Perhaps the recent publication by the Coleman Institute of the declaration on "The Rights of People with Cognitive Disabilities to Technology and Information Access," will lead to a much stronger appreciation of just how central smart technologies can be to supporting their more self-determined lives.

2. My personal involvement

The potential of technology to enhance self-determination has been a core interest for the last 15 years. That interest has been focused on making that potential possible in health care through small research projects that have changed to reflect the ever-increasing power of smart technologies to allow us to provide opportunities for self-report and self-direction in their experience of care by people with IDD. New smart technologies seem to have the ability to empower most people who experience them. Why should people with IDD be left out?

3. Barriers to changes in policy and practice

Some of the barriers to the more widespread adoption of technology as a tool for self-determination include:

- **Cost:** There are no current service planning and reimbursement models for the technology access, training, and support central to truly individualized, self-determined models of services and support.
- **Justification:** There are no large-scale or integrated studies to date showing the impact and cost benefit of technology on the development and achievement of self-determined service plans.
- **Technical Support:** There is a need for 24/7 access to call centers for troubleshooting services and support.

4. Opportunities for system change and innovation

Some promising practices:

- The “Living the Smart Life” video from AbleLink Technologies illustrates how smart technologies enable and promote self-determination and independent living in the community. <http://www.ablelinktech.com/index.php?id=32>
- An accessible version of the AHRQ CAHPS Patient-Centered Medical Home, Patient experience survey, is designed to enable direct response to survey questions on their health care experience by people with IDD (developed from the AbleLink Technologies ATLAS (Accessible Testing Learning & Assessment System) software. <http://www.ablelinktech.com/index.php?id=139>
- An adaptation of the CQL Personal Outcome Measures survey supports the more cost-effective use of this individualized service planning tool to maximize participation and direct response to survey questions by people with IDD.
- An Oral Health promotion study for people with IDD is currently under review by the National Institute of Dental and Craniofacial Research. Based on the WIHD/ AbleLink application—My Health, My Choice, My Responsibility— which promotes health planning, health education, and prompted and coached preventive health activities all under the direct control of an individual with IDD, with the capacity for cloud-based individualized care planning and automated response generation on participation health and wellness activities. <https://itunes.apple.com/us/app/my-health-my-choice-my-responsibility/id428382635?mt=8>

In the United Kingdom there is a realization that the demographics of the aging and long-term care populations are at odds with the continued availability of a direct care workforce to meet those needs. This has led to support for some large-scale pilot projects designed to maximize the use of assistive technologies of all kinds to support innovation in the creation of future care models that promote independent living in the community. These projects—Developing Assisted Living Lifestyles at Scale—are in their infancy, but the rationale behind them and the anticipation that technology might play a key part of service evolution is not.

<https://www.innovateuk.org/documents/1524978/2274828/DALLAS+-+Delivering+Assisted+Living+Lifestyles+at+Scale+-+Competition+brief/29e8d709-453b-4e91-ab04-dfbao3do362b>

In the United States there are some lessons to be learned from the use being made of health information technology under the Affordable Care Act, particularly the strategies being used to capture the individual’s experience of services under the Patient-Centered Medical Home model of care. These include both the definition of what “patient-centered” means, the tracking systems put in place to measure what is being achieved, and a system of incentive payments for meeting performance standards.

<http://www.ncqa.org/Programs/Recognition/PatientCenteredMedicalHomePCMH.aspx>

The State of Self Advocacy in 2013: Reflections, Barriers, and Next Steps

CAU Symposium | October 2013

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The State of Self Advocacy in 2013: Reflections, Barriers, and Next Steps

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1. Background

Over the course of the last several decades, we have seen a consistent expansion in the rights and opportunities available to people with intellectual and developmental disabilities. From *PARC v. PA* and the passage of Public Law 94-142 to the Americans with Disabilities Act and the Supreme Court's landmark *Olmstead v. L.C.* decision, we are in the midst of the greatest expansion in integration and equality of opportunity for people with I/DD in the history of the world. Despite this, the extraordinary gap between people with I/DD and the general public in terms of rights protection, health and employment outcomes, and other relevant metrics is both a stark indictment of the depths of where the I/DD field started and a reminder of the extraordinary scope of remaining work necessary to realize true equality for people with I/DD.

The disability rights movement is unique among major American social movements in that the social and attitudinal barriers faced by people with disabilities began to fall largely after the legal and political victories won by this movement. Contrast this with other civil rights movements in America, where changing societal attitudes preceded legal and policy victories. For example, while the disability community has a far more extensive set of federal law and policy achievements (i.e., the ADA, Olmstead, IDEA, etc.) as compared to those of the gay rights movement, in much of the United States the GLBTQ community today has far greater momentum toward achieving meaningful social inclusion than the disability community, particularly among the younger generation of Americans.

How to account for this disparity? One explanation can be found in the curious contradiction present in most I/DD advocacy: while advocates have as their stated goal to advance the autonomy, integration, and self-determination of people with I/DD, most of the key decision-makers in the I/DD advocacy movement are not themselves people with I/DD. The general public notes this contradiction and, as a result, discounts the capacity of people with I/DD for self-determination given that the most prominent proponents of this argument come from a family member or from provider communities. Additionally, the family and provider communities are key components of the I/DD advocacy movement but they each possess their own set of distinct goals separate and sometimes contradictory to those possessed by people with I/DD themselves. Family members may frequently wish to prioritize safety (and thus their own peace of mind) for their children with I/DD, even if the children themselves would rather face greater risk in less restrictive environments. Providers have a vested economic interest in maintaining their existing business model and maximizing revenue while minimizing costs. In each instance, those with the most power in the I/DD advocacy movement possess incentives

and motivations that are at cross-purposes with maximizing the integration and equal opportunity of people with I/DD.

In recent years, the self-advocacy movement has emerged to challenge the family and provider constituencies for control of the I/DD advocacy movement. While self-advocacy groups—defined here as groups in which people with I/DD make up a majority of both board members and paid staff—view the family and provider stakeholder groups as necessary allies in the broader disability rights movement, they also believe that only self-advocates have the moral authority and lack of conflicting incentives to lead the I/DD community's advocacy efforts. In the last several decades, the concept of self-advocacy has garnered significant acceptance in the I/DD community.

Self-Advocates Becoming Empowered (SABE) estimates that there are 1,200 local self-advocacy groups in the United States. Taking into account the growing number of self-advocacy groups with more specific focuses, such as those affiliated with the Autistic Self Advocacy Network or the National Youth Leadership Network, that number may be even higher. Self-advocacy groups focused on a specific community may bring a critical disability rights-oriented perspective to sectors that have previously lacked the values framework offered by the I/DD movement; this includes efforts by autistic self-advocates to push back against cure-focused advocacy and restrictive service models in the autism world. Others, such as youth self-advocacy groups or those rooted in racial and ethnic minority communities, may attempt to call greater attention to groups that are going underserved by mainstream I/DD advocacy organizations. Internationally, at least 43 other countries have established national self-advocacy organizations. Increasingly, the presence and strength of the self-advocacy movement in an area can serve as an important metric of the health and level of progressivism of the local I/DD movement in that area.

2. Barriers faced by the self-advocacy movement

Despite the recognition of the importance of self-advocacy, self-advocacy organizations remain substantially weaker than I/DD organizations run by family members and provider groups. In 2011 and 2012, the Administration on Intellectual and Developmental Disabilities convened a series of nine self-advocacy summits covering the entirety of the nation to assess the state and scope of the self-advocacy movement in the United States. The final report from the summits noted that while the self-advocacy movement was widespread, it suffered from low levels of funding, lack of paid staff, struggles with advisers who attempt to control groups rather than empower self-advocates, challenges in recruitment and development of new leadership, and conflicts with more powerful family and provider organizations seeking to control self-advocacy as another funded “program” rather than a movement.

There are a variety of barriers to the full realization of the self-advocacy movement's potential. This paper will endeavor to outline some of them and potential strategies that self-advocacy groups, allies, and funders may undertake in addressing these concerns.

2.1 Economic Barriers

Poverty is an ever-present reality in the lives of most people with disabilities, particularly those with I/DD. While family organizations can typically tap parents or siblings with financial resources or fundraising experience, and provider organizations have financing for their operations built into their business model, self-advocacy groups lack a ready source of financing. According to the 2012 report from the Allies in Self Advocacy Summits, a majority of state self-advocacy organizations reported that their state Developmental Disabilities Council funded self-advocacy, as required by the DD Act. One-third of states reported that they received some level of funding through their state developmental disability service agency. Recently, the Administration on Intellectual and Developmental Disabilities funded three cooperative agreements with self-advocacy organizations to provide technical assistance to state and local self-advocacy groups on enhancing their capacity. To date, however, the vast majority of self-advocacy groups lack diversified funding streams and live grant to grant, without any sustainable funding for a paid self-advocate executive director through which fundraising, governance, or systems change expertise and relationships might accumulate.

2.2 Leadership Experience

Perhaps as a result of the challenges posed by the lack of a sustainable funding stream, the self-advocacy movement has a disturbingly small cadre of leaders schooled in program management, nonprofit governance, fund development, staffing and management, and other key skill sets. To date, efforts to rectify this have taken two extremely different forms. Many self-advocacy groups have utilized the existing funding they do possess to hire non-disabled advisers to assist in nonprofit governance, grant-writing, and other activities where few people with I/DD possess previous career experience. While often successful in performing those functions, non-disabled advisers also frequently exert an inappropriate level of control and influence within organizations supposedly run by people with disabilities. Furthermore, as many advisers are affiliated with a disability service-provider, many self-advocacy organizations become captive to the interests and priorities of a particular service-provision agency or the provider community as a whole. Finally, the long-term use of non-disabled advisers results in a loss of opportunities for people with I/DD to develop the necessary skill sets to run and manage a successful nonprofit organization, perpetrating the problem the use of non-disabled advisers was intended to solve.

The second response to the leadership gap faced by the self-advocacy movement is investment in the recruitment, cultivation, and development of new leaders with I/DD. The Partners in Policymaking program has long invested in the cultivation of both family member and self-advocate change agents in public policy advocacy. Additionally, the growing proliferation of youth-focused self-advocacy organizations offers a significant opportunity to bring in and invest in emerging leaders to the self-advocacy movement. Some self-advocacy groups have formed their own leadership development programs. For the last two years, the Autistic Self Advocacy Network (ASAN) has run the Autism Campus Inclusion Summer Leadership Academy, a weeklong leadership training for autistic college students focused on grassroots

organizing tactics, systems change skills, and other aspects of leadership development. In 2014, ASAN will be utilizing funding from AIDD to establish a West Coast version of the program focused on emerging self-advocate leaders of all ages and across the entirety of the I/DD community. ASAN will also be launching a state-based version of the program, beginning in Tennessee, where it will focus on preparing self-advocates to play a role in that state's Employment First efforts.

2.3 Infrastructure

While self-advocacy groups exist across the United States, their relative weakness and dependence on the DD Network and service-provider community limits the degree to which the self-advocacy movement could meaningfully be said to possess a national infrastructure capable of pursuing its goals. Unlike the Independent Living movement, which offers technical assistance to smaller Centers for Independent Living as they emerge and work to develop into more effective service and advocacy entities, self-advocacy groups are not typically in a position to offer significant resources or technical assistance to emerging self-advocacy organizations. Unlike the Statewide Independent Living Councils or state and national independent living associations, the self-advocacy movement's coalitions of individual groups are comparably weak and relatively recently established. Some progress has been made on these issues thanks to leadership provided by the Administration on Intellectual and Developmental Disabilities through the Allies in Self Advocacy Summits, which led to the establishment of numerous state self-advocate coalitions, and other initiatives. The recent AIDD investment in regional technical assistance cooperatives for self-advocacy may begin to address this barrier, yet additional investment will be required to meaningfully alter the status quo.

3. Solutions

The rise of the self-advocacy movement remains one of the most promising and important developments in the I/DD community today. To realize the full potential of the self-advocacy movement, self-advocacy organizations—along with their allies among other stakeholders and funders—must consider taking steps to address the significant economic, leadership, and infrastructure challenges faced by the movement. While there are many potential solutions that could help contribute to addressing these problems, the following recommendations are put forward as a starting point to jumpstart further discussion and debate.

3.1 Building the Financial Sustainability of the Self-Advocacy Movement

While support and investment from the DD Network will remain a critical component of the movement's funding for the foreseeable future, self-advocacy groups must begin to build a base of funding that is not entirely dependent on other stakeholders in the I/DD community. Self-advocacy organizations should begin working to cultivate foundation funders. Particular emphasis should be placed on cultivating relationships with funders with an interest in health, education, and disability issues, as well as those who focus funding on a particular geographic

area in which a self-advocacy organization has roots. Self-advocacy organizations also have significant potential for revenue from earned income. Trainings, speaker's honoraria, publications, and other similar areas should be explored for their potential to provide sustainable revenue streams not dependent on the decisions of a single funder.

3.2 Matching Investment Fund for Self-Advocacy

Allies and funders in the I/DD space also possess opportunities to cultivate the fund development capacity of the self-advocacy movement through the use of matching funds and other mechanisms designed to encourage self-advocacy organizations to develop new funders and sustainable programs. Funders should consider the establishment of a Matching Investment Fund for Self-Advocacy. Established with funds from existing funders and DD Network stakeholders, such a fund could be administered by national self-advocate leaders and could be used to make grants to state and local self-advocacy groups, with the requirement that all funding be matched on a 1:1 basis by investments from outside the DD Network.

3.3 Supporting Leadership Development

The cultivation and expansion of a cadre of self-advocate leaders capable of being effective change agents and skilled in nonprofit governance, fund development, and program management knowledge represents one of the most critical needs for the self-advocacy movement. Funders and other stakeholders should work to establish, support, and expand leadership development programs that support emerging new leaders in the self-advocacy movement as well as professional development for existing leaders at the local, state, and national levels. Existing models include the Partners in Policymaking program, the Youth Leadership Forums, and the ASAN Leadership Academies. In addition, DD Network partners and other I/DD advocacy groups should work to create career opportunities for self-advocates within their own organizations. By hiring self-advocates or creating internship and fellowship opportunities targeted to self-advocacy movement emerging leaders, such groups can help facilitate the transfer of critical skills to the self-advocacy movement.

3.4 Technical Assistance Infrastructure

Since 1977, the independent living movement has made use of the Independent Living Resource Utilization's IL-NET collaborative to provide technical assistance to Centers for Independent Living and Statewide Independent Living Councils. Unfortunately, no corollary exists for the I/DD self-advocacy movement. AIDD's recent investments in regional self-advocacy technical assistance consortia may provide the "skeleton" for such a project in the future. Public and private funders should closely monitor the newly established technical assistance consortia established by AIDD and explore the possibility of building upon them for the purposes of establishing a national infrastructure for technical assistance and sharing of promising practices to and between self-advocacy organizations at the local, state, and national levels. Any such technical assistance infrastructure will by its very nature need to be

both governed and implemented by one or more self-advocacy groups rather than by provider, family, or research stakeholders.

4. Conclusion

To fulfill its true potential, the self-advocacy movement—and those who wish to support it—must begin to directly challenge the barriers facing the movement’s growth and progress. Self-advocacy groups must begin to rely more extensively on self-advocate leaders rather than non-disabled advisers. Growing diversity in self-advocacy movement leaders offers an opportunity to accomplish this; different self-advocates will possess different skill sets, challenges, levels of experience, and ability. Furthermore, through the development of new strategies and resources on financial sustainability combined with an expanded leadership development and technical assistance infrastructure, self-advocacy organizations will have greater capacity for effective change than ever before. While much will need to be done to implement these recommendations, careful and strategic efforts can and will empower people with I/DD to take charge of their own destiny. It is the sincere hope of the author that the I/DD community will work to support this necessary evolution.

New Directions for Advocacy

CAU Symposium | October 2013

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New Directions for Advocacy

CAU Symposium | October 2013

1. Overview of Community Access Unlimited

Community Access Unlimited is a nonprofit social service agency. Incorporated in 1977, the agency became active on May 7, 1979. Its purpose or mission is to enable people with disabilities to be productive, independent citizens living real lives integrated into a real community, and to use all its resources to achieve those ends.

CAU provides direct services to those we support—that is, people with disabilities who are members of CAU, who have a developmental, emotional, physical, or social disability, and those who fall through the cracks of the social service system.

Our services include:

- Helping people to achieve integration into welcoming and accepting communities
- Supporting people to be economically self-sufficient, living independently, paying taxes, and controlling their own money
- Supporting people to be knowledgeable and demanding of their civil rights
- Helping people realize their own personal growth and development in healthy social and professional capacities

We at Community Access Unlimited are not naïve to think that we can achieve those ends for our members in a vacuum. We understand that we do not live in a vacuum; we cannot establish a Utopia by waving a magic wand or wishing something to be true when it is not. We understand that we cannot achieve our end goals while 1% of the population owns almost half the wealth; when racism, sexism, and bigotry are encouraged; and when 90% of the population is encouraged to divide into special interest groups.

Therefore, CAU understands there must be a social movement that embraces its values and beliefs. A movement that is inclusive of all people and strives for all people to become productive, independent citizens living real lives integrated into a real community.

2. An effective social movement

CAU believes that the movement must have:

- A broad, diverse network of people and organizations firmly grounded in a system of shared values
- An evolving agenda of short- and long-term issues and outcomes
- Democratic participation and collaboration that cultivates solidarity, reciprocity, and mutual responsibility

- The capacity to catalyze the activism of others

We believe that developing and participating in this type of movement will result in a self-sustaining base of collective knowledge and power that can successfully leverage progressive change toward full social, political, and economic equality.

We believe this movement needs to be:

- Influencing important issues, decisions, and policies
- Expanding resources for community-based, non-institutional social services
- Continually regenerating social movement connectivity and leadership

And it is essential that this movement include power centers that are independently funded, controlled, and managed by people with disabilities.

Community Access Unlimited believes this Social Movement Goal is an essential end. CAU believes that its values and beliefs cry out for it to invest its resources into its achievement.

3. **Aligning for a common goal**

We at CAU realize we are moving on new grounds, following an approach not yet tried.

- We have many questions; we understand we have few answers.
- We need to get the younger generation of leadership to join us.
- We need to develop and educate others and ourselves.
- We have questions on how to protect ourselves as bad times are coming.
- We have questions on the economics of social services and society itself.
- We have questions on how to launch a movement of power and values together yet keep control where it belongs.

This is why it is essential to periodically link together with others who are traveling this road with us.

Community Access Unlimited holds joint meetings with other boards, people with disabilities, and state and national leaders to discuss policy and to identify common goals to implement.

4. **Defining new approaches to combat rising inequality**

There have been very few, if any, new approaches over the past 20 years in the field of disabilities. Supported Employment has failed to place people with the most disabilities; it has failed to replace segregated day programs and sheltered workshops. Often, micro-enterprises are very limited businesses that are free labor intensive, meaning that family members are often donating their time to help with the micro-enterprise. This model requires expensive supports that are often many times the value of the production of the business.

More people with disabilities are in very limited and rationed 'community capital-building' day functions that are not in general 5 days a week for 8 hours a day. Some of these 'community asset building' activities are free-labor intensive (i.e., with a family member) or are very financially expensive.

The U.S. economy is quickly adapting to 7% unemployment being the 'full employment' standard. Underemployment is becoming more the norm; and many people have left the employment world discouraged. National corporations and the financial investors follow the cheapest labor force around the globe.

The age of neoliberalism has furthered the income inequality of the United States as well as the globe. In the United States since 2008, 95% of the wealth and income generated has gone to the top 1%.

The bottom 80% has yet to see a real increase in income after inflation for over 30 years. Assets such as pensions, 401Ks, and home equity have been transferred from the bottom 80% to the top 10%.

Since the mid-1970s, the wealthy power elite has funded neoliberal think tanks and foundations that have led to the shrinkage of social functions in government; privatization; and the reduction of social supports for the environment; safety and food regulations; social services; affordable housing and subsidies such as Section 8 vouchers; reduction of food stamps; aid to families in need; and attacks on social security, Medicare, and Medicaid. Concurrently, wealth transfers to the wealthy power elite have accelerated to agro-business; oil companies; and military-related industries to name just a few. And recently more than \$3 trillion dollars in wealth was transferred through the Federal Reserve Bank to the financial houses that are "too big to fail." Earning less than 0.5% of interest in a CD while the bank loans money out at over 4.5% has created one of the widest profit margins in recent banking history.

Bigotry, racism, and rugged individualism are on the rise. The U.S. government does not even recognize the UN protocol on Human Rights for People with Disabilities.

You can change the label while the devaluation and disempowerment increases concurrently for people with disabilities.

Community, family, and the social contract between society and its government and its citizens are being torn up.

The most fundamental right in a democracy—the right to vote—is being withdrawn throughout the country. The Supreme Court decision, *Citizen's United*, allows the wealthy power elite to directly purchase its political privileges. Industries, both directly and through foundations, fund groups to actively interfere with the rights of others to demonstrate, petition, and to be heard. We have become a democracy for Corporations, but of course, they are people too.

Social Services has marched unwittingly with the neoliberal drums, embracing privatization and managed care and the rationing of supports concurrent with the engorgement of the wealthy

power elite from the wealth of the government through techniques such as indirect subsidies, tax cuts and tax loopholes, and other transfer-of-wealth financial gimmicks; to the impoverishment of its citizens through cutbacks; the failure and destruction of a real labor movement; the divide-and-conquer tricks of the power elite; and the cost shifts onto the backs of the bottom 80%.

We must stop self-flagellations and thinking out of the box. For example, why eliminate sheltered workshops in the name of integration? Why not insist they become an integrated workforce with their boards controlled by sheltered-PWD employees and families?

People with disabilities are among the most vulnerable, least employed, and poorest of our citizens.

6. What is to be done?

Frederick Douglas once stated that "Power is not given, it is taken." Self advocacy even in the best of economic times, were invited to the power table, 'empowered' by others, which means no power. Self-determination is a fraud. Without the economic and political power to exercise it, consumerism is a position of passiveness and dehumanization. The self-advocacy group soon becomes the main course served at the table.

Even at the best of times, most self advocates received not a single dime toward their own self-funded, self-governed power centers or organizations.

Now it is becoming the worst of times. The Great Recession ended June 2009, so we are at the end of the good times. Advocates and their allies must step forward and learn the tools of organizing, learn self-respect and self-reliance, become educated to history and economics, learn to capture resources, gain and use political power, and be able to either sit at the table of power as equals or be able to crush the opposition. The movement must be able to work in coalition with others.

7. The basic tenets

Community Access Unlimited (CAU) has come to the conclusion in its early history that people with disabilities will not become fully valued citizens living and belonging in the community until all people are. An injury to one is an injury to all.

The Board of CAU has organized itself on basic tenets and has embarked on a journey to help spark the progressive movement.

The Global Governance Commitment

The Board of CAU has developed a Global Governance Commitment, which is:

To build coalition with those organizations and individuals who hold a preponderance of similar basic beliefs/values and approaches which if achieved will allow people with disabilities to be productive, independent citizens living real lives integrated into a real community.

These basic values/beliefs are:

1. *Community integration*
2. *Holistic interactions as valued human beings*
3. *Equal treatment as citizens*
4. *Choice and self-determination*
5. *Real lives in real homes*

And to achieve a society of political, economic, and social equality, and respect to develop a Social Movement policy, which is that:

CAU and its members bring leadership and participation to a community-inclusive social movement that achieves all people being productive, independent citizens living real lives integrated into a real community.

The movement has:

1. *A broad, diverse network of people and organizations firmly grounded in a system of shared values*
2. *An evolving agenda of short- and long-term issues and outcomes*
3. *Democratic participation and collaboration that cultivates solidarity, reciprocity and mutual responsibility*
4. *The capacity to catalyze the activism of others*

There is a self-sustaining base of collective knowledge and power that successfully leverages progressive change toward full social, political, and economic equality:

1. *Important issues, decisions, and policies are influenced*
2. *Resources for community-based, non-institutional social services are expanded*
3. *Social movement connectivity and leadership are continually regenerated*
4. *There are power centers that are independently funded, controlled, and managed by people with disabilities*

8. Social Movement Advocacy Steps

Since its inception, CAU has been active in implementing its Social Movement policy through distinct stages.

1. Self Advocacy
 - Helping Hands
 - TOP-MAC
 - Hotline with Paid Advocate Staff
 - Drop-In Center with Paid Advocate Staff

Goals of social life/redress grievances of services and supports/direct new and or improved supports and services/build self-image, self-confidence, and self-reliance; learn how to conduct meetings, bylaws, protocol, democracy

2. Educational Advocacy

- Jump Start
- MAC Attack
- Advocates with leadership positions within CAU and local/county/state/national level
- NAMPWD: Education of the leadership in self-advocacy and its allies

Goals of self education; ability to teach, present, use leadership skills, train others on what needs to be done to provide required and requested supports, learn how to run a business

3. Political Advocacy

- Power politics around issues
- Voting/Government
- Staffed
- Participation in demonstrations, persuasion advocacy
- Organizing around central issues for people with disabilities and other oppressed groups such as closing institutions/civil rights/economic, social, and political justice
- Expansion of Section 503/504 to include all businesses that receive funding from the federal government, whether by grants/contracts or tax incentives: Bring in areas as the agri-businesses; defense; oil companies; financial institutions.

Goals of building a base both within CAU, the advocate world, and within social service organizations/learn power politics/educated on higher level of social-political information, put theory to practice and social policy building

4. Coalition With Others, Building Advocacy

- Panels and workshops at other events
- Advance education of and with all fields on inequality/poverty/equality/citizenship
- Organizing and education of leadership and opinion makers of various groups

Develop allies' organizations such as currently being done locally:

- Interfaith Project
- Anti-poverty non-profit Self Help Project and Social Policy Building
- Adolescent Network Project: The Forgotten Generation and Social Policy Building
- Coalition/Education of trade organizations
- Re-booting progressive social research and place into action

The Future of Participant Direction

CAU Symposium | October 2013

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The Future of Participant Direction

CAU Symposium | October 2013

1. Overview

Building from person-centered planning and growing out of self-determination philosophy and principles, participant direction (also known as consumer direction or self-direction especially in the behavioral health community) means that the participant has choice and control and can exercise a considerable degree of flexibility in meeting his or her needs and goals for long-term services and supports (LTSS). The Centers for Medicare & Medicaid Services (CMS) describe two types, or levels, of participant direction: employer authority, where the participant can hire, manage, schedule, train, and dismiss direct care workers; and budget authority, where the participant manages a budget and determines, within broad parameters, how that money is used to hire workers and/or to purchase goods and services to live more independently at home. Individuals with participant direction options have a range of supports available—from financial management services that help with issuing paychecks, filing taxes, and record-keeping to support broker (or counseling/coaching) services to support the participant in developing and implementing a spending plan, finding resources, locating training options, managing workers, etc. The participant can even select a representative to assist with his or her duties within the program. Participant direction is a voluntary option; people can return to traditional agency-delivered services at any time.

Research has shown participant direction to be highly effective in meeting the needs of people with very different types of disabilities. The model is highly robust. Also, research has shown that in Arkansas's participant direction program, Cash & Counseling, nursing facility use was 18% lower for the treatment group than for the control group during a 3-year follow-up period.¹

In the United States, recent research from the National Resource Center for Participant-Directed Services (NRCPS) shows that more than 800,000 individuals are self-directing under the employer or budget authority models. Every state has at least one employer authority option, and 44 states offer budget authority programs. The growth of Veteran-Directed Home and Community Based Services (VD-HCBS) assures us that every state will soon have the budget authority option as well.

Some contend that the growth of participant direction has been rapid. To a great extent, this can be credited to:

- Powerful research results from the participant-directed Cash & Counseling Demonstration and Evaluation; these were widely disseminated and translated into

¹ Dale, S., & Brown, R. (2006). Reducing nursing home use through consumer-directed personal care services. *Medical Care*, 44(8), 760-767.

journal articles for researchers, issue briefs for policy leaders, toolkits for program managers, and readable booklets for legislators, the media, and the general public

- Legislation like the 1915(j) provisions in the Deficit Reduction Act of 2005 and authorizing language in the last Older Americans Act reauthorization (2006)
- Supportive regulations and policies such as the new 1915c waiver template
- Advocacy from national organizations and participants themselves

Others wonder why participant direction has not spread faster, especially given that research by the AARP Public Policy Institute shows that 75% of surveyed members would want to manage their own services rather than use agency-directed care should they need help with activities of daily living (ADLs). It is clear that America is becoming more diverse by the day, and one size does not fit all. Participant directed options provide opportunities to individualize spending plans and respond to cultural differences and preferences. But, without clear expectations and well-planned training, participant direction is in danger of being watered down—the words becoming just a meaningless platitude. Continued research is needed to streamline the model, showing program managers it need not be onerous to implement.

2. Opportunities and barriers to the growth of participant direction

Opportunities and barriers to the growth of participant direction are intertwined. Let me address a few:

2.1 Managed long-term services and supports (MLTSS)

Within the next two years, 26 states will, or intend to, deliver home and community-based services through managed care arrangements. The NRCPPDS has just completed work on a technical assistance tool entitled “Selected Provisions from Integrated Care RFPs and Contracts: Participant Direction in Home and Community-Based Services” under contract with Mathematica Policy Research for the CMS Medicare-Medicaid Coordination Office, as well as a paper entitled “Participant-Directed Services in Managed Long-Term Services and Supports Program: A Five State Comparison” under contract with Truven in partial fulfillment of a Task Order from the Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation. These papers, which can be found at participantdirection.org, detail some of the issues in defining participant direction, urging states to offer budget as well as employer options, setting data collection requirements expectations, and meeting the training needs of Managed Care Organization care coordinators and supervisory staff.

2.2 Integrated care

As efforts unfold to integrate acute care, LTSS, and behavioral health care, the current ways of delivering participant directed LTSS will need to morph and adapt. Issues abound, including:

- How person-centered (or patient-centered/member-centered) planning can be infused across settings in an efficient way.

- How participants can be brought into the service planning process.
- How, with the participant's approval, a participant's hired workers can take on more health maintenance tasks previously done by nurses.
- How, with the participant's approval and oversight, direct care workers can receive individualized training on the "red flag" issues important to their employers and then bring problems to the attention of the rest of the team.
- How the representative's role can change as participant's needs, particularly behavioral health needs, fluctuate.

Because of the flexibility of the model, and its malleability in responding to individual needs, the participant direction approach is uniquely positioned to assist in these more holistic efforts.

2.3 Needs for training, especially for support brokers

The New York Community Trust recently awarded a grant to the Council of Social Work Education and the NRCPS to work with nine social work programs to develop modules for infusing person-centered planning and participant direction competencies into their bachelor's and master's degree programs. The need for a paradigm shift to help present and future support brokers and their supervisors move from a "professional knows best" to an "empowerment" framework is critical for the growth of participant direction.

2.4 Opportunities for participant direction to spread to new populations and service arenas (e.g., veterans, behavioral health, long-term care insurance, and even private pay arrangements)

A good deal of the recent growth in participant direction programs is attributable to the Veterans Health Administration's commitment to offer VD-HCBS at every VA Medical Center in the next few years. This effort is important in its own right, and it also helps establish the infrastructure necessary for other funders to build on. In the behavioral health area, recent small demonstrations of participant direction in Florida, Pennsylvania, Texas, and the United Kingdom are leading to interest in a major large-scale demonstration and evaluation to further examine cost issues and systemic effects.

3. CONCLUSION

Clearly, participant direction options have tremendous potential to improve or maintain people's lives as illustrated by the following testimonials:

We're confronting old-fashioned ideas, and for many, many years, people that have received services were told they could not recover and there were not possibilities and dreams for them. And we help to empower people and keep shifting that paradigm that many things are possible.

—Self-direction program staff

Being in the system you feel like you can just drop off and you don't matter as a person, you're just a number. With [self-direction] you feel like an individual, you have value, and that gives you hope.

—Self-directing participant

When I was diagnosed, I ... didn't think I had a right to think or my opinion didn't matter because I felt so bad about being mentally ill. And [self-direction] sort of turned me around on that. I started making my own decisions, and even contemplating what could make me better, taking on a healthy attitude.

—Self-directing participant

It's my own money, I'm more careful with it ... I'm building skills and having to do research to see how much things cost ... I try to do as much as I can myself.

—Self-directing participant

Before closing, I would like to emphasize a few additional role(s) for participants. The more participant direction evolves the more we realize the participant's role is NOT just at the individual level. Evidence is mounting that peer supports and peer counseling can make a substantial difference, and that participants can have a positive impact on the design, implementation, and evaluation of programs.²

² Chinman, M., Young, A., Hassell, J., & Davidson, L. (2006). Toward the implementation of mental health consumer provider services. *The Journal of Behavioral Health Services and Research* 33(2), 176-195.
Min, S.Y., Whitecraft, J., Rothbard, A., & Salzer, M. (2007). Peer support for persons with co-occurring disorders and community tenure: A survival analysis. *Psychiatric Rehabilitation Journal*, 30(3), 207-213.
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Income Inequality, People with Disabilities, and Public Policy

CAU Symposium | October 2013

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Income Inequality, People with Disabilities, and Public Policy

CAU Symposium | October 2013

1. Introduction

By now, most are familiar with the pattern of growing income inequality that affects the nation at large. Few, however, are aware of how disabled people as a demographic fit into the overall income inequality picture. As detailed below, the available data indicate that disabled individuals are particularly hard hit by growing income inequality. Even more troubling, however, is that the prospects for addressing income inequality—both writ large and for disabled people as a sub-group—through the public policy arena are quite dim, all due to the growing national acceptance of "fiscal retrenchment" as a desirable policy norm at both the federal and state levels.

2. The data on income inequality trends

According to the most recent Census data, incomes have either stagnated or declined over the last couple of decades for all but the wealthiest 10%. From the end of the Great Recession in June 2009 through December 31, 2012, the top 10% not only earned back everything they lost during the Great Recession (a decline in income of 11.3%), but have seen real income growth of just under 15%. The wealthiest 1% have fared even better, seeing real income growth of 31.4% during the recovery (after a loss of 16.3% during the recession).

The vast majority of Americans, however, have not been so fortunate. Indeed, the bottom 90% of income earners in the United States, whose income declined by 13.7% during the Great Recession, saw their real earnings drop by another 1.8% during the "recovery" that followed.

Tracking how disabled individuals have fared in this environment is somewhat more difficult. Fortunately, every three years the Census Bureau publishes a report entitled "Americans with Disabilities," which provides a fair amount of socioeconomic information. The following data are from the July 2012 "Americans with Disabilities" report, which has data through 2010. According to the Census Bureau, in 2010:

- Approximately 56.7 million people, or 18.7% of the total U.S. civilian non-institutionalized population, had a disability.
- About 38.3 million—or 12.6% of the total non-institutionalized population and some 67.5% of individuals with a disability—had a severe disability. The Census defines a severe disability as: (i) any mental or emotional condition that seriously interferes with everyday activities; (ii) a condition limiting the ability to work around the house or make it difficult to remain employed; or (iii) one or more

specified conditions, such as autism, cerebral palsy, mental retardation, other developmental disabilities, using a wheelchair, cane, crutches or walker, or being unable to perform functional activities such as walking, using stairs, or grasping objects.

- The total number of people with a disability increased by 2.2 million or 4% between 2005 and 2010.
- The Asian population had the lowest disability rate (14.5%) and the African American population had the highest (22.2%); the Hispanic population had a rate that was not statistically different from the rate for the non-Hispanic White population—both at roughly 17.4%.
- Only 4 in 10 individuals aged 21 to 64 years old with a disability were employed (41.1%), compared with 8 in 10 adults without disabilities (79.1%).¹
- People aged 21 to 64 years old with a severe disability were less likely to remain consistently employed over a 24-month period (19.9%) compared with people with non-severe disabilities (54.8%) and people with no disabilities (61.1%).

Given that employment data, it is hardly surprising that adults aged 21 to 64 with disabilities typically earned less than workers who were not disabled. In fact, median household income for people with disabilities was just \$34,272 per year in 2010.² That is only 60% of the \$57,252 median annual household income of people without disabilities in 2010, and it ranks in the bottom 40% of all income earners.³ Because of the tremendous growth in income inequality between the top 10% and everyone else in America overall, it can be assumed that disabled individuals have fared particularly poorly, given that their median income ranks in the bottom 40% of all earners. Indeed, individuals with disabilities had higher base poverty rates and persistent poverty rates than those with no disability.⁴

3. Concerns raised by fiscal retrenchment

Traditionally, the public sector has pitched in to assist vulnerable populations like disabled individuals attain a higher quality of life and access to opportunity. One would expect no less in the richest nation in the world. So, it is no surprise that almost 60% of the 38.3 million people with severe disabilities received some form of public assistance.⁵ At the federal level, Social Security and Medicaid have been particularly important. Of the \$357 billion in federal spending that went to services or programs that support individuals with disabilities in 2008,

¹ Disability rates involving work related data (earnings, employment rates, etc.) are for individuals aged 21-64. Disability rates or data concerning "adults" with a disability covers individuals aged 15-64.

² Carmen DeNavas-Walt, Bernadette D. Proctor, Jessica C. Smith, *Income Poverty and Health Insurance Coverage in the United States: 2012* (Washington, DC; September 2013) 9.

³ Matthew W. Brault, *Americans with Disabilities: 2010 Household Economic Study* (Washington, DC; July 2012) 12.

⁴ Ibid.

⁵ Ibid.

\$169.8 billion took the form of income support benefits while \$169.1 billion was in healthcare.⁶ In 2010, an estimated 34.6% of the 38.3 million adult Americans with a severe disability participated in Medicaid, accounting for 42% of all Medicaid payments.⁷

Obviously, the social safety net is quite important to disabled individuals. It is also in jeopardy due to the acceptance of "fiscal retrenchment" as a policy goal. Under this approach to fiscal policy, running a budget deficit is deemed to be a problem that should be addressed primarily through spending cuts rather than appropriately designed revenue enhancements.

The current federal focus on deficit reduction—as implemented through initiatives such as sequestration—have thus far left Social Security unscathed. Programs provided through discretionary spending authorized for the Department of Health and Human Services, however, have not been so fortunate; these have been cut by some \$3.99 billion, or 5.6%, in FY2013 alone. In fact, when mandatory spending authority cuts for the Department of Health and Human Services are included, overall spending for the department in FY2013 will be cut by some \$15.5 billion from FY2012 levels.⁸

At the state level, fiscal retrenchment has impacted Medicaid in many instances, and most human service programs overall. Consider Illinois as an example. That state has the fifth largest economy in the United States, with an annual Gross State Product in excess of \$672 billion for calendar year 2012. That said, due to its ongoing structural deficit problems, Illinois cut its Medicaid programs by some \$1.6 billion in FY2013. This continues a long-term trend of Illinois cutting spending on healthcare in real terms since FY2000, as shown in Figure 1.

Figure 1. Healthcare Appropriations FY2014 vs. FY2000 Actuals, Adjusted for Inflation and Population (\$ Millions)

Category	FY2000 Enacted	FY2000 Enacted Infl & Pop Adjusted	FY2014	Difference between FY2014–FY2000 Adj	% Diff FY2014 GOMB & FY2000 Adj
Healthcare (excluding Group Health Insurance)	\$5,022	\$8,911	\$7,171	(\$1,740)	–19.5%

SOURCES: FY2000 UNADJUSTED APPROPRIATIONS FROM GOVERNOR'S FINAL BUDGET SUMMARY FOR FY2000; AND FY2014 CLBA ANALYSIS OF OPERATING BUDGET DETAIL GOMB, FY2014 OPERATING BUDGET DETAIL (MARCH 6, 2013), [HTTP://WWW2.ILLINOIS.GOV/GOV/BUDGET/PAGES/BUDGETBOOKS.ASPX](http://www2.illinois.gov/gov/budget/PAGES/BUDGETBOOKS.ASPX). APPROPRIATIONS ADJUSTED USING MIDWEST MEDICAL CARE CPI FROM THE BUREAU OF LABOR STATISTICS AS OF JANUARY 2013, AND POPULATION GROWTH FROM THE CENSUS BUREAU AS OF JANUARY 2013.

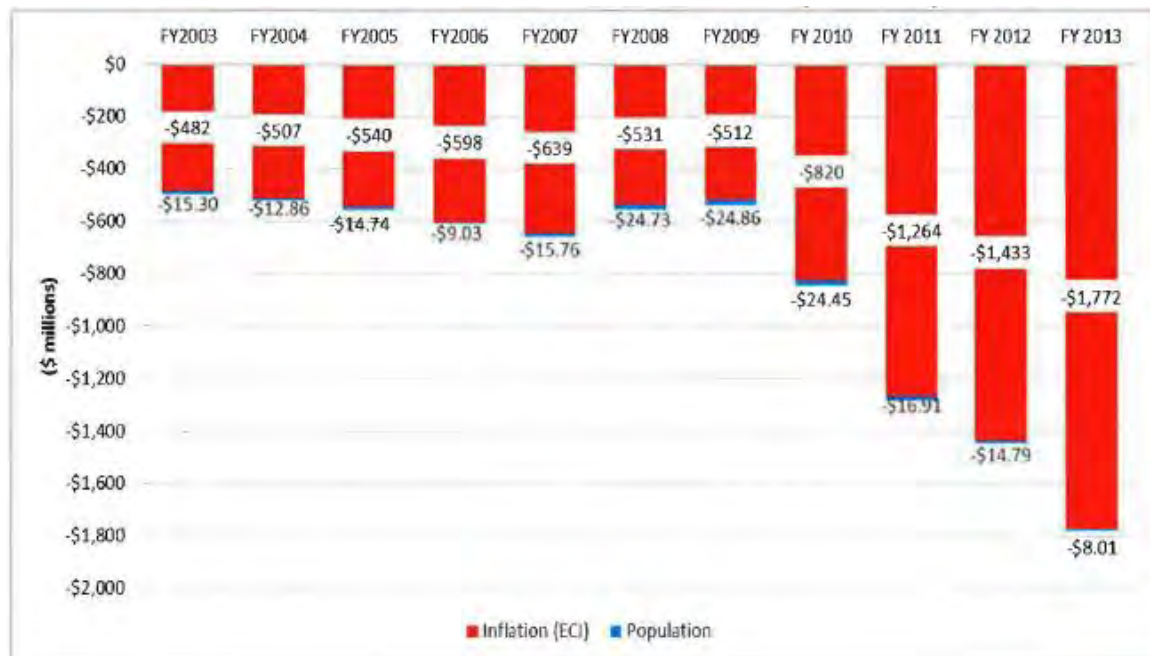
Human services in Illinois have fared even worse over time, as shown in Figure 2.

⁶ Gina Livermore, David Stapleton, and Meghan O'Toole, Federal Expenditures for Working-Age People with Disabilities in Fiscal Year 2008 (Maryland; April 23, 2012) PowerPoint Presentation, slide 6.

⁷ Kaiser Family Foundation: State Health Facts, Distribution of Medicaid Payments by Enrollment Group FY2010 <http://kff.org/medicaid/stateindicator/payments-by-enrollment-group/>.

⁸ Office of Management and Budget Report to Congress on the Joint Committee Sequestration for FY2013 (Washington, DC; March 1, 2013).

Figure 2. Cumulative Cut in Human Service Spending Since FY2002 Adjusted for Inflation and Population Growth (\$ Millions)



SOURCE: COMMISSION ON GOVERNMENT FORECASTING AND ACCOUNTABILITY, BUDGET SUMMARIES FOR FY2002 TO FY2009, GOMB DATA FOR FY2010 TO 2013 GENERAL REVENUE APPROPRIATIONS FOR THE ILLINOIS DEPARTMENTS OF AGING, CHILDREN & FAMILY SERVICES, AND HUMAN SERVICES. APPROPRIATIONS SHORTFALLS NECESSARY TO MAINTAIN REAL VALUE OF FY2002 APPROPRIATION BASED ON NATIONAL EMPLOYMENT COST INDEX (ECI). POPULATION GROWTH ESTIMATES FROM CENSUS AND ILLINOIS DEPARTMENT OF COMMERCE AND ECONOMIC OPPORTUNITY.

Countering the pernicious impact that growing income inequality has on disabled individuals requires robust investment in social safety net and economic programs designed to help disabled people realize their potential, earn a livelihood, and enjoy a decent quality of life. That cannot happen if the federal and state governments continue down the path of fiscal retrenchment.

Poverty and People with Intellectual/Developmental Disabilities

CAU Symposium | October 2013

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Poverty and People with Intellectual/Developmental Disabilities

CAU Symposium | October 2013

1. Overview

There is a well-established association between indicators of (low) socioeconomic position (SEP) and the (increased) prevalence of intellectual disabilities in childhood.^{1, 2} While the association is most evident for children with less severe intellectual disability, more recent research has suggested a modest but significant social gradient in the prevalence of more severe intellectual disability and autism.²

Three distinct causal pathways have been identified that may contribute to the observed social gradient. First, an extensive literature has documented the links between low socioeconomic position and the increased risk of exposure to a range of environmental adversities (e.g., under nutrition, less-stimulating parenting) that may impede cognitive development, particularly for young children.³⁻⁵ Second, a modest literature has documented the increased direct and opportunity costs associated with parenting disabled children. If these costs are not compensated for by welfare payments they could increase the risk of downward social mobility of families supporting a disabled child.^{6, 7} There is, however, little (if any) direct evidence that child disability is associated with differential family poverty trajectories over time during childhood.⁸ Third, 'exogenous' factors (e.g., low parental intelligence, parental substance abuse) may independently lead to increased risk of low socioeconomic position and an increased risk of intellectual/developmental disability.⁹

2. Why is this important?

The prevention of intellectual disability

The incidence and prevalence of intellectual (and some other developmental) disabilities could be reduced by:

- Reducing exposure to low SEP
- Reducing exposure to specific adversities associated with low SEP
- Developing interventions that ameliorate the impact of exposure to specific adversities associated with low SEP

For example, we have (rather crudely) estimated that under nutrition alone may be responsible for a 75% increase in incidence of intellectual disabilities in low-income economies.¹⁰

The prevention of health (and other) inequalities faced by people with intellectual/developmental disabilities

We commonly attribute the poorer health (and other adversities) experienced by people with intellectual/developmental disabilities (I/DD) to either the impairments associated with I/DD or discriminatory (disablist/ableist) social practices. It is likely, however, that they also reflect the impact of increased risk of exposure to low SEP during childhood. For example, we have estimated that increased risk of exposure to low SEP during childhood accounts for 20% to 50% of the risk of poorer mental and physical health among children with general intellectual impairments;¹¹⁻¹⁴ and most or all of the risk of poorer mental health and low rates of well-being among mothers of children with disabilities or general intellectual impairments.¹⁵⁻¹⁷

3. What needs to be done?

Some very initial thoughts:

Reframe the discourse

The link between I/DD and poverty/low SEP is noticeably absent in disability policy discussions/documents in most high-income countries. It is also noticeably absent (with some honorable exceptions) in the I/DD research community. Effectively addressing the health and social inequalities faced by people with I/DD will require us to take a broader approach to understanding the determinants of these inequalities. We need to get the link between I/DD and poverty/low SEP on the agenda.

...and build alliances

The I/DD policy/practice/research community is very insular. At an international level, poverty/inequality reduction policies are central to the work of many United Nations (UN) agencies—both as an objective in its own right and as a strategy for reducing health inequalities. Unfortunately, while notions of disability-inclusive development are gaining credibility and traction (e.g., UNICEF's 2013 State of the World's Children report, UN high-level meeting in September), the social determinants of health movement(s) have largely failed to show any understanding of (or interest in) disability.¹⁸ Building alliances with these initiatives could be beneficial to all. It would almost certainly, however, need to be approached in terms of disability rather than I/DD.

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Inequality

CAU Symposium | October 2013

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Inequality

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1. Introduction

As a researcher and more recently as a campaigner, my work has focused on the social damage suffered by societies that have very large income differences between rich and poor. Now that we have internationally comparable data, we can see that the old intuition that inequality is divisive and socially corrosive is even truer than we imagined. More unequal societies suffer from dramatically worse outcomes in many different areas, including physical and mental health, violence, child wellbeing, bullying in schools, drug abuse, imprisonment, low social mobility, obesity, and social cohesion.¹ There seem to be few if any benefits to offset this: the balance of the evidence does not suggest that inequality is good for growth or a spur to innovation.^{2, 3}

Asked to be provocative, I should point out that inequality is a problem particularly for the United States (and only slightly less so for Britain). Of the rich developed market democracies, the United States is among the most unequal. As a consequence, it compares unusually badly with other rich countries in terms of outcomes such as life expectancy and mental health, homicide, social mobility, incarceration, drug abuse, and obesity. In all these fields it is one of the worst performers. In contrast, more equal countries—particularly those in Scandinavia—do well on all these kinds of measures.

2. Inequality and social dysfunction

Greater inequality leads to widespread signs of a general social dysfunction because it weakens community life and damages the social fabric and the quality of social relations throughout society. The larger the material differences (both income and wealth) between people, the bigger the social distances between them and the more important class and status become. Most important are the psychosocial effects of inequality that affect differences in ideas of self-worth, superiority and inferiority, and our worries about how we are seen and judged in these terms.

This affects disability and the lives of people with special needs because inequality leads to a not-so-subtle shift in what life seems to be about. Status competition and status insecurity become more important to the detriment of ideas of reciprocity and the common good. Life

¹ Wilkinson, R. & Pickett, K. *The spirit level: Why greater equality makes societies stronger*. (Bloomsbury Publishing USA, 2010).

² Herzer, D. & Vollmer, S. Inequality and growth: evidence from panel cointegration. *The Journal of Economic Inequality* 10, 489-503 (2012).

³ Page, S. E. & Vandermeer, J. Inequality and Innovativeness. *Economics Bulletin* 33 (2013).

becomes more dominated by getting ahead, by self-promotion and self-aggrandisement—increasing the importance of money and consumerism because it is through them that we express status. There are now careful international studies showing that inequality leads to a culture of narcissistic self-aggrandisement as status becomes more important.^{4,5} The emphasis that increased inequality places on hierarchy and social position means not only that people are more 'out for themselves' but also that forms of downward prejudice and discrimination increase as well. As we come to judge others more by social status, prejudice against more vulnerable minorities and the less well-off increases. This particularly affects ethnic minorities, lower social classes, women, and those with disabilities.

Research using multilevel methods and controlling for average income levels, social expenditure, welfare regimes, and individual socioeconomic characteristics found that people in more unequal societies are less likely to say that they would be prepared to do something to improve the conditions of each of four categories of people: people in their neighborhood, the elderly, sick or disabled people, or immigrants.⁶ These effects of inequality were found among both high and low income groups. A series of other research studies, both experimental and observational, have found that high social status increases antisocial behavior—people appear more 'out for themselves'.⁷ Larger inequalities in Britain have been accompanied by a decrease in public willingness to provide adequate government support to the disabled or permanently sick and more suspicion that people in these categories are abusing the system.

3. The rise of inequality

The United States used to be one of the more equal societies. The modern rise of inequality has taken place largely since the 1970s. Between c.1980 and the early 2000s, pay differentials between CEOs and production workers in the largest 350 companies increased from approximately 35:1 to around 350:1.⁸ There are few more powerful ways of telling a whole swathe of the population that they are almost worthless than to pay them less than one-third of 1% of what a CEO is paid. On top of the widening difference in pre-tax incomes has been a dramatic decline in top tax rates.

4. Reducing inequality

There are a number of different approaches to reducing inequality. But first, it is important to realize that in the more unequal of the developed capitalist market economies (including the United States and the United Kingdom) the gap between the richest and poorest 20% of the

⁴ Loughnan, S. et al. Economic inequality is linked to biased self-perception. *Psychological science* 22, 1254-1258, doi:10.1177/0956797611417003 (2011).

⁵ Neville, L. Do economic equality and generalized trust inhibit academic dishonesty? Evidence from state-level search-engine queries. *Psychological science* 23, 339-345 (2012).

⁶ Paskov, M. & Dewilde, C. Income inequality and solidarity in Europe. *Research in Social Stratification and Mobility* (2012).

⁷ Piff, P. K. Wealth and the inflated self class, entitlement, and narcissism. *Personality and Social Psychology Bulletin* (2013).

⁸ Mishel, L. & Sabadish, N. Pay and the top 1%: How executive compensation and financial-sector pay have fuelled income inequality. (Economic Policy Institute, 2012).

population is twice as big as in the more equal of these countries (such as Norway, Sweden, the Netherlands). A very major transformation is needed and it can only be achieved by a sustained social movement committed to this objective over the next 10 or 15 years. The easiest initial targets are tax avoidance and tax havens, but we also have to make taxes more progressive again.

Probably more important in the long term than redistribution are policies to reduce income differences before tax. It looks as if the bonus culture reflects a lack of any democratic restraint at the top. Reducing pay differences before tax requires a long-term objective of extending democracy into our economic institutions. Whether as campaigners or as consumers, we should support all forms of economic democracy: many EU countries already have legislation requiring employee representation on company boards or remuneration committees. German law requires that in companies with more than 2,000 employees, 50% of the members of Supervisory Committees are worker representatives. However, we also need to support other forms of economic democracy, including mutuals, employee-owned companies, and cooperatives. We should take our custom to these institutions and governments should be encouraged to increase tax incentives to such companies and to set up funds to provide loans to assist employee buyouts. As well as having productivity advantages, it is said that an employee buyout can turn a company from being a piece of property into a community.

In Britain, local 'Fairness Commissions' have persuaded city governments in about 10 major cities to commit themselves to raising minimum wages from the legal minimum to what is known as the 'living wage' (32% higher in London and 18% higher elsewhere), and this has spread to other parts of the public sector and to some large private companies.

5. Enhancing social well-being

The objective is to build a society with a better quality of life for all. It is not only those with disabilities who depend on each other's kindness and cooperation: we all do. What is exciting is that we now have a policy handle on the psychosocial wellbeing of whole societies: by reducing income differences we can improve the quality of social relations and of the social environment for everyone.

The data show that rich societies have largely got to the end of what consumerism and raising material standards can do for the real subjective quality of human life: as countries get richer, having more and more of everything makes less and less difference to the important measures of happiness and well-being. As we begin to make the transition to an environmentally sustainable way of life, we must turn our attention from raising material standards to improving our social well-being.

Managed Care

CAU Symposium | October 2013

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Managed Care

CAU Symposium | October 2013

1. Overview

The onset of a systemic change to a “managed care” delivery system presents enormous problems for individuals with disabilities, citizens who are poor, and citizens who are classically envisioned as “entitled” (seniors, fixed income, dependent, etc.). Under a managed care system, anyone who requires regular medical or support services (in-home, therapeutic, ADA skills, bathing, budgeting, etc.) will become categorically fixed under a purchase-of-service (POS) system with a specific financial rate attached to that person or service. Any deviation from that rate that requires flexible supports will be extremely difficult or nonexistent. Third-party vendors or managed care agencies will decide who should receive what services without regard to individuality, specific situations, or unique circumstances. The POS vendor’s motivation is to deliver the highest number of units of service for the least amount of financial resources. This is diametrically opposed to the current service system in many states.

2. How to address these barriers?

Unfortunately, the more a system is driven by a managed care/POS system, the less flexibility it can offer. Unless there are a variety of flexible options provided that address the unique service needs for citizens with disabilities, virtually everyone will become a unit of service with a specific amount of funds attached to that level of service. Any deviation from that amount will require additional, outside intervention and financial resources. A great example is the current Medicaid system of health care. Medicaid purchases “X” for anyone with a Medicaid card, depending on the specific state in which they reside. Should they wish to have “Y” services, they either need to purchase that service independent of Medicaid or do without. Certain doctors will accept Medicaid while others will not. Additionally, since Medicaid is “means” dependent, with specific income and asset limitations, anyone receiving Medicaid will not (or should not) have the financial resources to purchase “Y” services. The system will perpetuate both systemic dependency and poverty.

One must also recognize that this issue also perpetuates a system of haves and have-nots along with an incredible growing gap between economic classes. Under the developing “Obama Care” or the Affordable Care Act, everyone will have to acquire basic medical services or be covered under the state-optional expansion of Medicaid. That system of universal health care will also provide an option for individuals to acquire additional, expanded health care services for a premium price, very much like the current system under Medicare. Medicare covers medical services under “Plan A,” and these services are defined universally for everyone who is entitled. But if an individual or family wants additional services such as prescription coverage, dental coverage, or expanded medical coverage, they are offered “Plan B” or “Plan C” for an

additional premium. Those who have financial resources and desire different or expanded coverage can acquire services that others may not be able to afford. Again, this separate-but-equal option will continue to separate those with resources from those without.

Lastly, under this impending systemic change, the concepts inherent in self-determination, systemic advocacy, and personal choice and preference will be eliminated or severely weakened. Currently several states offer a system of block funding that allows individuals to control funds used for their acquisition of specific, desired services. The concept of self-determination allows an individual personal choice and preference to acquire those things offered by various vendors, family members, etc. Any funds allocated are the responsibility of the individual who decides. Unless there is a specific “carve-out,” these options will not be possible under a managed care system—unless strong legislation allows for this type of option prior to the onset of managed care.

Other unresolved systemic issues include:

- What role will quality assurance play in managed care?
- Who will fund advocacy and what role will advocates play in the developing system?
- Will self-determination be possible and how will the POS system be reviewed?
- States have enrolled in a series of Medicaid “waivers” that offer specific options to wrap services around specific needs for citizens with disabilities. What will happen to these waived options under the managed care system?
- Many of us have worked extremely hard to develop ways in which individuals can get out of poverty by creating investment options for things like housing? Will those options be available under the impending managed care system?
- What will happen to the large number of people on Medicaid waiver waitlists for services? They don’t get basic services now, so what will happen if they don’t get them in the near future?
- What will society do with all the poor people who will face certain death without basic supports?

3. Impact on Housing

We all need basically the same things within our community:

- Positive relationships with others
- Support services and assistance
- Income or a way to pay for things
- A role in which others perceive us as a contributing member of our community
- A place to live which we call home

There has always been a significant disparity in income levels in society, and it is well recognized that those with the greatest incomes often define what life should be or will be for

those with less. The upcoming significant changes defined through managed care will not lessen this dramatic disparity. For people who are in greatest need of all of the above community needs—that is, those with the least amount of income and the greatest dependency on community—this disparity will only grow worse.

Levels of Need

Housing policy defined by the department of Housing and Urban Development (HUD) recognizes the intensity of need based on income levels. When compared to a local or regionalized income level, HUD reviews what is called the Area Median Income (AMI) to identify greater levels of need. For example if an AMI for Newark, NJ is \$50,000 for the average individual income and someone is at “50% of AMI,” they are considered to be comparatively at about \$25,000 per year or half of the norm in income. This is a significant issue used to identify levels of needs for the allocation of resources. When someone is at “30% of AMI” or approximately \$15,000 per year (30% of \$50,000) they are considered to be of substantially greater need. Most of the individuals served who are classified as developmentally disabled have income levels at or below 15% of AMI, or approximately \$8,000 per year. These citizens represent a class of poverty that should mandate the greatest allocation of resources.

All housing financial resources (Section 8 housing subsidies, housing programs such as Section 202, 811, HOME or CHIP funds, etc.) are—or should be—directed toward meeting the needs of those at or below 50% of AMI. Additionally, rules indicate that those same resources should provide a significant allocation toward those with the “greatest needs,” generally defined as those “at or below 30% of AMI” which should include most individuals with disabilities. Unfortunately, this statement of fact is not forthcoming in policy.

Parity Payments

In HUD housing policy, the expectation is that an individual and/or family will spend approximately 30% of their income toward housing. For people who are considered poor, HUD provides a “rent subsidy” program called the “Section 8” program. The intent of the subsidy is to provide a “parity payment” which makes up the difference between the fair market rent (FMR) and 30% of someone’s income. To simplify, if the AMI is \$50,000, the fair market rent for a one bedroom would suggest to be \$1,200/month ($\$50,000 \times 30\% / 12 = \$1,200$). A rent subsidy for someone at 50% AMI might be calculated accordingly as \$25,000 (50% AMI) times 30% or \$7,500 or \$625/month, thus requiring a rent subsidy of \$575/month to bring the individual up to the parity or FMR of \$1,200/month. Accordingly, someone at 30% AMI (\$15,000/year) would require a rent subsidy of \$825 per month ($\$15,000 \times 30\% = \$4,500$ or \$375 per month versus FMR of \$1,200). Of course someone at 15% AMI simply will require more. Current HUD policies mandated under the recent “sequestration,” along with the economic conditions of the country, has seen Congress significantly reduce the HUD Section 8 program. Again, people with limited incomes are getting substantially farther behind.

Greatest Need, Least Opportunity

There are a series of recent reports that have substantiated the hardship placed on those with the greatest financial needs. Produced by TAC in Boston, an ongoing series entitled “Priced Out” provides a yearly analysis that compares AMI levels by state, including metropolitan areas, and reviews rent levels compared with those at 50% and 30% AMI and those who receive SSI as their sole source of income. TAC has found that there is no community in America that offers a simple one-bedroom apartment for 100% of a person’s SSI income. This fact illustrates how far behind people with significant disabilities are from the rest of their community.

People with significant disabilities also have the least amount of economic opportunity to correct this incredible disparity. Without substantial assistance, most individuals are not likely to gain competitive employment status and produce income levels that will allow for removal from their poverty status. The characteristics that define “significant intellectual or cognitive disabilities” indicate that most of those we support are not likely to attend college or develop trade skills that lead to competitive employment and further income levels. Moreover, these citizens maintain a functional level that may also require substantial support services (assistance with daily living skills, budgeting, transportation, medical assistance, etc.). Income levels for most of those we support are simply not sufficient to pay for these support services, and Medicaid (public insurance) is often the reliant source for paying for these supports.

Self-Determination and Housing

Lastly, those with significant disabilities (at or below 30% AMI) will be required to live with someone else with a disability, whether they wish to or not. The economics of community living will require a minimum of at least two (often three or four) individuals to live together to justify the housing economics. Subsequently, the issue of “relationships” becomes a significant issue with anyone developing affordable housing. Individuals with disabilities often do not choose who they wish to live with independent of others in their community. Supportive housing entities factually develop housing and pair individuals without regard to conflicting personalities, rhythms of their lives, comparative lifestyles, or even outside relationships. Decisions are often made based on urgency of need or length of time on a waiting list versus a true choice based on a positive relationship developed over a period of time. There is nothing unique about people with disabilities living together versus all blonds, social workers, or executive directors; the odds of developing positive working relationships for people we support are no greater than anyone else. The more we assist individuals to live with those with whom they can develop meaningful relationships the better off we all become.

Challenges Posed by Managed Care

In housing, managed care will challenge –

1. The economics of housing will require people to live with others. How this is addressed will truly define not only the quality of life but also how we conceive of “self-determination.”

2. There has never been a time where the significant economics of disabilities clearly illustrate just how far behind people with disabilities are from others in their community. Without financial assistance from rent subsidies, the risk or demand of group living is inevitable.
3. We need to refocus housing opportunities toward people developing positive, meaningful relationships with others, regardless of disability, with whom they wish to live and perhaps share supports and support providers.
4. Managed care will place all vulnerable people at risk of losing their community and required supports unless they have a voice in the process. I am not convinced this level of advocacy is included in anyone's planning process.
5. Income disparity is clearly separating people by class and support requirement dependency. Those who require the greatest level of support are at risk of losing the greatest sense of belonging, care, and community.

These are but a few of the many critical factors coming under the impending "managed care system" of human services.

Using the New Medicaid Home and Community-Based Services Authorities to Advance System Reform

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Using the New Medicaid Home and Community-Based Services Authorities to Advance System Reform

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1. Description of the topic area

Over the past few years, new opportunities for Medicaid financing of home and community-based services (HCBS) have come into play. One new authority, the **1915(i) State Plan Home and Community-based Services (HCBS)** option, permits states to offer home and community-based services to new populations who were not previously eligible for a broad array of Medicaid-funded supports and services in their homes and communities. Although HCBS have a long history that begins with the 1915(c) HCBS waiver program in 1981, access to these services has been limited to individuals who meet eligibility for institutional services. The 1915(i) State plan HCBS option “decouples” the institutional eligibility requirement, requiring eligibility criteria for the program be “less stringent” than the criteria for institutional eligibility. States have the option of including any services that could be covered in the 1915(c) HCBS waiver program. States may design the program as “cross-disability” or target the program to specific individuals. Although the program is an entitlement to all those who qualify, states may define a group by age or diagnosis of condition and must define “needs-based criteria” as eligibility requirements. Needs-based criteria may be as diverse as the need for assistance with daily living activities or the need for long-term supports to achieve employment; additionally, they can include risk factors such as homelessness. While the state cannot cap the numbers served, it can make the benefit open to a broad or narrow group and can limit the benefit (units of service). Another new resource is the **1915(k) Community First Choice (CFC)** which provides states a 6% increase in federal funding for services that assist with activities of daily living, such as personal care, and other supports to increase independence in the individual’s own home as well as in community residential settings, including 24-hour services. Eligible individuals must meet criteria for institutional eligibility. States cannot target the benefit to specific individuals; all those who meet institutional eligibility and have an assessed need for the covered services are entitled to receive services.

2. What’s hot about these options?

- 1915(i) provides the opportunity to bring comprehensive Medicaid-funded HCBS to individuals who do not meet an institutional level of care or who have never been eligible for HCBS.
- Under 1915(i), creation of an entitlement to all eligible individuals for HCBS services, with, at state option, either a broad or narrow definition of the group(s) to be served.

- Additional funding under CFC for what a state may already be doing, potentially allowing for expansion of services if the state reinvests the additional funding.

On the plus side, 1915(i) in particular holds promise for supporting populations who previously did not have access to Medicaid-funded HCBS services. For decades, our field has raised concerns about the “institutional bias” in Medicaid. Finally access to HCBS has been decoupled from institutional eligibility, permitting states to fund services to populations they could not previously serve with Medicaid funding. While the 1915(c) waiver is a very successful and positive program (serving more than 600,000 individuals with I/DD nationally and with every state participating), there are individuals with disabilities who need supports and services to be successful community members who do not meet the waiver’s institutional eligibility requirements. Individuals who do not meet the stringent intellectual functioning eligibility criteria (that is, an I.Q. higher than the state’s “cut-off” for HCBS waiver services), individuals with primarily mental health needs, or those with needs for supports that do not “rise” to the institutional level of care criteria are left out of Medicaid-funded HCBS, leaving states to fund individuals with state funds only—or worse, leaving these folks without the supports they need, requiring them to deteriorate until they are at risk of institutionalization.

For the 34 states that already offer a State plan personal care option, or states that have any type of entitlement to personal care and/or residential services (states such as California and now Oregon), CFC provides additional funding for the services that states already deliver.¹ (See below for concerns about this as well.) If a state funds State plan personal care services, which is an entitlement to any individual qualifying for the services (the person has ‘medical necessity’ for the service), it makes sense for the state to move these services to CFC and get an additional 6% increase in Federal Financial Participation (FFP). CFC may also make sense if a state has no waiting list for any population seeking residential services under the HCBS waiver.² Since CFC is an entitlement to all those who meet Level Of Care (LOC) and have a need for the services, states have to carefully assess the impact of opening up an entitlement even with the increased revenues. Oregon, on the plus side, made the decision to fund a full array of personal care and residential supports on a 24/7 basis on their CFC option, making an entitlement to these services for individuals who meet LOC and have an assessed need for the services. If the state were to shift individuals who receive personal care and/or residential services under the HCBS waivers to this benefit, this could also increase revenue and potentially provide some resources to either increase access to services or make improvements in other areas of the system—and, of course, create an entitlement to the supports the state chooses to cover.

The 1915(i) option allows states the option to offer a wide array of HCBS to individuals who previously could not qualify for these services. Finally the institutional bias of Medicaid has been upended, allowing those with significant needs—but not eligible for Medicaid-funded

¹ State Health Facts, Kaiser Foundation: <http://kff.org/medicaid/state-indicator/personal-care-services/>

² The University of Minnesota report, *Residential Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2011* indicates that 9 of 42 states furnishing data had no waiting list for residential services for individuals with I/DD. Data for other populations is not known.

institutional services—access to the support they need. Individuals whose primary issues are around mental health and substance abuse, individuals with mild disabilities but significant behavioral challenges, individuals with criminal justice involvement, kids “aging out” of foster care—now, each of these can be afforded the full array of supports. They are no longer limited to just the State plan “rehab” or clinic services but supported employment, supportive housing, respite, family training—whatever specific set of supports makes sense for the population can be offered. As an example, one state decided, in support of their cross-disability employment first initiative, to create a 1915(i) benefit that offers supports to gain and sustain employment to *all* individuals with disabilities seeking employment. The state can now offer employment supports (beyond what individuals can get from vocational rehabilitation services) to individuals with visual impairment or other individuals with no cognitive impairments, such as individuals on the autism spectrum, who could never qualify for a HCBS waiver but who need support to achieve and sustain employment. Moreover, 1915(i) can offer people support in other areas such as social skills or financial management or could be used to intervene before individuals’ needs rise to the level that makes them eligible for the HCBS waiver. Colorado, for example, offers services under 1915(i) to individuals with chronic health conditions as a means to prevent deterioration and the need for more intensive supports.

3. What might not be so hot about these options?

Understandably, states are looking for revenue. (Although the economy is recovering, the Center for Budget and Policy Priorities notes that 31 states had budget shortfalls for FY 2013; even if growth were as high as 8.3% per year, it would take until 2019 to restore budgets to pre-recession amounts.³) But if not carefully thought through, the act of revenue-seeking to fill budget “holes” may have unintended consequences. For example, moving all personal care and residential services to CFC without careful deliberation could result in a “homogenization” of services. Since CFC is cross-disability and requires a universal functional assessment with a set of core questions (states may use multiple, disability-specific assessments as long as each assessment includes certain core questions), the areas of disability-specific services, expertise, and focus might be at risk. How the benefit is managed is also essential to its programmatic success. Who will oversee a cross-disability benefit? How are the program agencies involved since this is a State plan benefit (which are typically under the direct management of the Medicaid agency)? How will the state offer a “seamless” set of HCBS when potentially there are multiple Medicaid authorities and managing entities involved? And states may end up “shoehorning” existing residential services into a more limited scope of services—potentially losing the person-centered, “building a life” aspect of supports.

There are also concerns surrounding the 1915(i) benefit. States may be tempted to divide up broader disability groups into smaller segments that offer a highly limited benefit in order to make sure they can meet the entitlement aspect of the program. Since 1915(i) also has limits on which Medicaid income eligibility groups can be served, some individuals—particularly those

³ <http://www.cbpp.org/cms/index.cfm?fa=view&id=711>

who are working with incomes above 150% of poverty level—are not eligible for 1915(i). States will have to be careful to make sure, if they move services out of the HCBS waiver programs or other benefits such as the State plan rehabilitation or clinic options, that working individuals have continued access to needed supports.

4. Results of system change on the outcomes of people with IDD

Using these new authorities we can:

- For the first time, offer Medicaid-funded HCBS—supported employment, behavioral supports, supported living, in-home supports—to individuals who cannot qualify for the HCBS waiver but sorely need supports. For example, individuals with mild developmental disabilities but significant primary mental health services—could get individualized, customized HCBS funded through Medicaid.
- Craft targeted programs that specifically assist individuals with highly specialized needs such as individuals with dual diagnosis, children with autism, and individuals with I/DD in the criminal justice system. These are just a few of the ways that states could craft a 1915(i) benefit.
- Prevent deterioration to the point where individuals qualify for the institutional level of care—getting to folks **before** their needs are extensive.
- Undergird cross-disability efforts such as statewide Employment First initiatives, making employment services an entitlement and priority to all individuals with disabilities.
- Garner additional funding for community-based residential and personal care services that could help to expand services, perhaps funding some services for individuals on waiting lists.

BUT, we must be careful not to:

- Sacrifice high-quality, disability-specific services and expertise in exchange for increased revenues.
- Homogenize our programs to fit the authority rather than using the authority to undergird our programs.
- Divide our programs into smaller and smaller increments, serving tightly targeted tiny segments of the overall population—potentially creating more complexity and fragmentation in our systems.